

**Educational Provision and Support for
Persons with Autistic Spectrum
Disorders: the Report of the Task Force
on Autism**

October 2001

FOREWORD

This report on the *Educational Provision and Support for Persons with Autistic Spectrum Disorders* could not have been produced without the assistance of many people. Firstly, I would like to acknowledge the commitment, dedication and expertise of the Members of the Task Force itself. The Task Force was composed of a combination of parents, education and health professionals, advocates and researchers. The Final Report represents the outcome of the synergy which arose from the debates and insights provided from these five perspectives. In terms of debate, drafting and editing the Report is truly a team effort. However, in particular, I would like to acknowledge the dedication of the Secretary to the Task Force, Mr. Micheál Ó Flannagáin, whose researches, perseverance, and meticulous attention to detail sustained the work of the Task Force throughout the development and finalisation of the Report. The support given to the members of the Task Force by their families and employers is also acknowledged with gratitude.

Underlying this Report, providing an essential foundation for its analysis, were the submissions which were received from a wide range of individuals and groups. The Task Force is deeply grateful to all who took the time and trouble to make these submissions and also, in many cases, to provide very valuable supporting documentation. The Task Force appreciates very much the courtesy and hospitality of people in the schools and service providers in the Republic, in Northern Ireland and in Great Britain visited by members of the Task Force and who gave so generously of their time.

The Task Force benefitted greatly from the insights of a number of experts from Ireland and from other jurisdictions. In particular, thanks are due to Dr. Philip Strain, Ms. Martha Ziegler and Ms. Patricia Guard of the United States and members of the Northern Ireland Task Force on Autism, chaired by Mr. Martin Clarke. The Task Force also gratefully acknowledges the advice so generously given on constitutional and legislative issues by Professor Gerard Quinn and Ms Shivaun Quinliven of the Disability Law and Policy Research Unit, Faculty of Law at the National University of Ireland, Galway. The Task Force was very much supported in its work by the quiet efficiency of Mr Martin Shiel of the Department of Education and Science who always facilitated but was never obtrusive. Invaluable support was also provided by Ms Ann Colgan who did the summary analysis of submissions with insight and empathy. Essential secretarial support was given by Ms Ailish Doyle and Ms Alice Byrne of the Education Department at University College Dublin with their usual calm and cheerful organisation and support.

The wisdom and initiative of the Minister for Education and Science, Dr. Michael Woods, T.D. in establishing the Task Force on Autism has allowed the important issue of the education and support for persons with autistic spectrum disorders to be comprehensively explored for the first time in Ireland. His forbearance and facilitation of

the extension of the original deadline, as the Task Force grappled with this complex and sensitive task, is also gratefully acknowledged.

Finally, and above all, the value, contribution and needs of Irish citizens with autistic spectrum disorders is acknowledged and affirmed in this Report. It is my hope, and that of the Task Force, that this Report will provide a framework for the future development of a comprehensive and appropriate structure for education and support for this hitherto marginalised and misunderstood population. The completion of this Report represents not an end but a beginning.

Professor Sheelagh Drudy
CHAIRPERSON, TASK FORCE ON AUTISM
October 2001

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EDUCATIONAL PROVISION AND SUPPORT FOR PERSONS WITH AUTISTIC SPECTRUM DISORDERS

THE REPORT OF THE TASK FORCE ON AUTISM

Executive Summary

1. Dr. Michael Woods, Minister for Education and Science, launched the Task Force on Autism on 16th October 2000. The terms of reference of the Task Force were as follows:

- *Having regard to the distinct needs of certain children with autism;*
- *Having regard to the State's commitment to ensuring that the special educational needs of children with autism are properly addressed within the educational system;*
- *Having regard to the range of special educational provision and support services already made available to children with autism in special schools, special classes attached to ordinary schools and in integrated settings;*
- *Having regard to the desirability of ensuring that the services made available to children with autism reflect best international practice.*

The Task Force will:

- *Review the current range of educational provision and the support services available to children with autism in Ireland;*
 - *Assess the adequacy of current educational provision and support services, having regard to the range of special needs which can arise and the need to address such needs either in integrated settings or by way of special dedicated provision;*
 - *Make such recommendations as are considered appropriate for the development or adjustment of existing policy approaches, educational provision and support services, in order to ensure the delivery of an appropriate, effective and efficient educational service to children with autism;*
 - *Make such further recommendations, as the Task Force considers appropriate to the above matters.*
2. The Task Force held twenty meetings, some extending over two days, analysed documentation from 108 submissions, reviewed a wide collection of literature relating to autism spectrum disorder (ASD) and autism provision, and included visits to a number of schools and centres providing for children with ASDs in the Republic, in Northern Ireland and in England. A research paper, commissioned by the United States Department of Education, a meeting with leading American experts in autism and separately with the Northern Ireland Task Group on Autism assisted the work of the Task Force. Individual members of the Task Force also attended presentations by recognised practitioners in the field of autism in Dublin and Belfast and with representatives of the Department of Health and Children and the legal services.

3. This report is the outcome of the work of the Task Force and in its conclusion makes wide-ranging recommendations for the development of services for children with ASDs in Ireland. In all its work, it was evident to the Task Force that the capacity of current provision and resources has been, and is critically unable to meet the needs of all children with ASDs in Ireland, and that extensive strategic and practical changes are necessary to secure a range of provision, to train relevant professionals and to establish appropriate arrangements to guarantee the effective delivery of services to children and students with ASDs, and their parents, throughout Ireland.
4. Underpinning the findings of the Task Group is the urgent need for the Department of Education and Science to create structural provision for:
 - Inter-departmental co-operation
 - Regional ASD Educational Planning and Advisory Service
 - Identification, Diagnosis and Recording
 - Assessment of Educational Needs
 - Statutory Statement of Educational Needs
 - Appeals System
 - Review of Progress
 - Range of Provision: Early and Pre-school, First Level, Second Level, Third Level and Continuing
 - Curriculum Development
 - Inspection and Evaluation
 - Advisory and Training Support Services
 - Administration and funding.
5. The Task Force findings make it imperative that a co-ordinated approach is implemented by statutory bodies, most importantly, the Department of Education and Science and the Department of Health and Children. Accordingly, the Task Force recommends, as central to the development of provision, that the Department of Education and Science introduces legislation, which can be applicable to all children and adults with special educational needs, to establish, in law, a system for the formal identification, assessment and intervention in respect of young children and students with ASDs; to provide such arrangements within a given timescale, to provide an appeals procedure, and further, to include the formal involvement of parents throughout the process.
6. The essential policy and practices, which this report embodies, are that:
 - The needs of children with autism spectrum disorders are identified as early as possible and assessed comprehensively to inform intervention;
 - A range of provision is created and available to support the individual and unique needs of all children and young persons with autism spectrum disorders;
 - Priority is given to enrolment of the child's or young person in a mainstream school;

- There must be close partnership with the parents and co-operation between all the agencies concerned with provision;
 - There is a multi-disciplinary approach to the delivery and implementation of services;
 - All involved in the education and welfare of children with ASDs should be appropriately trained in a range of approaches and strategies;
 - Effective procedures are in place to monitor and evaluate the effectiveness of provision.
7. In reaching its conclusions, the Task Force endorses the findings of the *'Report of a Planning Group 'A National Support Service for Special Education for Students with Disabilities'* (Department of Education and Science, 2000) and regards the creation of a *National Council for Special Needs Education*, and the devolvement of administration to regional special needs organisers as effective structures which can be modified to promote and maintain the needs of children and young persons with ASDs.
8. Central to the Task Force findings is the need for the Department of Education and Science to indicate clearly the protocols and procedures for the ongoing monitoring and evaluation of ASD provision in order to inform and improve its quality, and warrant the necessary confidence and approval of parents and professionals.
9. To assist the further and future development of services, the Task Force findings indicate the need for the Department of Education and Science to fund research, in particular, into the effectiveness of various approaches and strategies used to educate children and young persons with ASDs, and into the national prevalence of ASDs. Where this is case, the Task Force prioritises for attention the particular needs of children and young persons with Asperger's Syndrome.

CHAPTER 1

INTRODUCTION

1.1 CONTEXT AND PRINCIPLES

This *Report of the Task Force on Autism*, submitted to the Minister for Education and Science, is dedicated to persons of all ages in Ireland who have autism or, to use the term this Report will employ most frequently throughout, autistic spectrum disorders (ASDs).

Autistic spectrum disorders affect people in a variety of ways. The litmus test for the quality of any society is the way it treats its potentially most vulnerable members. The time has come for Irish society to widen the base of its democratic structures by drawing those of our citizens who have autistic spectrum disorders in from the margins, and by prioritising and targeting their needs.

The approach to education taken by the Task Force on Autism is an emancipatory one. This approach is well expressed in the words of the great Irish educationalist, Professor Séamas Ó Súilleabháin:

The essence of education is becoming, the gradual discovery of what it means to be human, the search for a personal identity, an identity which brings individual autonomy within a community structure (Ó Súilleabháin, 1986, p.91).

Irish law has also defined education, particularly in the words of Chief Justice Ó Dálaigh in his Supreme Court judgment in the famous case of *Ryan v. Attorney General* [1965] I.R. 294:

Education essentially is the teaching and training of a child to make the best possible use of his inherent and potential capacities, physical, mental and moral.

International agreements and covenants to which Ireland is a party have also defined education. For example, the U.N. *International Covenant on Economic, Social and Cultural Rights* (ratified by Ireland and which interpretations by the Committee on Economic, Social and Cultural Rights are binding) in Article 13 on Education says the following:

1. *The States Parties to the present Covenant recognize the right of everyone to education. They agree that education shall be directed to the full development of the human personality and the sense of its dignity, and shall strengthen the respect for human rights and fundamental freedoms. They further agree that education shall enable all persons to participate effectively in a free society, promote understanding, tolerance and friendship among all nations and all racial, ethnic or religious groups, and further the activities of the United Nations for the maintenance of peace.*

2. *The States Parties to the present Covenant recognize that, with a view to achieving the full realization of this right:*

(a) Primary education shall be compulsory and available free to all;

(b) Secondary education in its different forms, including technical and vocational secondary education, shall be made generally available and accessible to all by every appropriate means, and in particular by the progressive introduction of free education;

(c) Higher education shall be made equally accessible to all, on the basis of capacity, by every appropriate means, and in particular by the progressive introduction of free education;

(d) Fundamental education shall be encouraged or intensified as far as possible for those persons who have not received or completed the whole period of their primary education;

(e) The development of a system of schools at all levels shall be actively pursued, an adequate fellowship system shall be established, and the material conditions of teaching staff shall be continuously improved.

3. *The States Parties to the present Covenant undertake to have respect for the liberty of parents and, when applicable, legal guardians to choose for their children schools, other than those established by the public authorities, which conform to such minimum educational standards as may be laid down or approved by the State and to ensure the religious and moral education of their children in conformity with their own convictions.*

4. *No part of this article shall be construed so as to interfere with the liberty of individuals and bodies to establish and direct educational institutions, subject always to the observance of the principles set forth in paragraph I of this article and to the requirement that the education given in such institutions shall conform to such minimum standards as may be laid down by the*

State (International Covenant on Economic, Social and Cultural Rights).

Having regard to these definitions, the Task Force sees education as a process which begins at the earliest stages of the individual's existence and which continues through life. Although the development of a personal identity and of individual autonomy is not confined to educational institutions, these are the structures established and financed by communities and the state, and charged with the provision of education. The Task Force recognises that, while much educational endeavour is designed to facilitate the growth of identity, autonomy, and maximum integration within the community, certain processes and structures within educational institutions may unwittingly become barriers to participation and success for marginalised groups such as persons with autistic spectrum disorders. For this reason, the focus in this Report is on formal education, and on the ways in which educational participation and success can be maximised for persons with autistic spectrum disorders.

The Task Force regards education as the key element in the achievement of equal status and maximum personal development for people with ASDs in our society. The aim of education can be well described as “to enable each pupil to discover the nature and scope of his or her particular potentials and limitations; to enable each and every pupil to make the most of these potentials; to overcome limitations wherever this is possible; to mitigate their effects where it is not” (Coolahan, 1994, p.8).

As we enter the twenty-first century we come at the end of a period of rapid educational change in Ireland. Many curricular changes have been proposed or have already been implemented. New structures have been proposed at all levels of the system (Department of Education and Science, 1992; 1993; 1995; 1999; 2000). For the first time in its history Ireland has a comprehensive Education Act as well as other recent legislation relevant to education (see Chapter Three). This period of extensive educational reform, and our current economic prosperity, undoubtedly presents an opportunity for Irish society to bring the education of people with autistic spectrum disorders in from the margins, and to clarify within the system the issues of status, independence, equal rights and empowerment. The work of the Task Force has been to critically review provision and existing legislation in order to provide the framework to put in place appropriate education.

The fundamental guiding philosophy of the Task Force is that of rights, equality and participation. This was the guiding philosophy of the work of the Commission on the Status of People with Disabilities (1996). Nine philosophical guidelines were set out in the Report of that Commission. Adapted to refer to children with autistic spectrum disorders they read as follows:

- Every child is educable. All children, including those with autistic spectrum disorders, have a right to a free and appropriate education in the least restrictive environment. Appropriate education for all children with autistic spectrum disorders should be provided in mainstream schools, except where it is clear that the child involved will not benefit through being placed in a mainstream environment, or that other children would be unduly and unfairly disadvantaged.
- Every individual has an equal right to educational provision, which will enable him or her to participate in all aspects of economic, social, cultural, and political life, to the fullest extent of his or her potential.
- The unique needs of the individual person must be the paramount consideration when decisions are being made concerning the appropriate provision of education for that person. In so far as is practical a continuum of services must be available to meet those needs close to the person's home and family.
- It is the responsibility of the state to provide sufficient resources to ensure that pre-school children, children of school-going age and adults with autistic spectrum disorders have an education appropriate to their needs in the best possible environment.
- Parents have primacy in the decision-making process as soon as their child with autistic spectrum disorders has been identified as having special educational needs. They [and the child whenever appropriate] must be entitled to make an *informed* choice on the educational placement of their child.
- There shall be an accessible appeals procedure on educational enrolment recommendations. This will have due regard for the rights of the child, the rights of the parents and the educational rights of other children.
- All schools have a responsibility to serve children with autistic spectrum disorders in the least restrictive environment. Each school plan must strive to make schools inclusive institutions. To facilitate inclusive education, due recognition must be given to the rights and needs of teachers for resources, initial education, and continuing professional development.
- Flexibility and formal linkages should be built into educational provision at local level. It must be a statutory duty of all existing or new management structures to secure access to high quality and appropriate education for all children and adults with autistic spectrum disorders.

- Priority should be given to the needs of people with autistic spectrum disorders, within the broad framework of educational provision, and this should be reflected in the allocation of resources.

1.2 TERMS OF REFERENCE OF THE TASK FORCE

Dr. Michael Woods, Minister for Education and Science, launched the Task Force on Autism on 16th October 2000. A list of members is given in Appendix 1. The terms of reference of the Task Force were as follows:

- *Having regard to the distinct educational needs of certain children with autism;*
- *Having regard to the State's commitment to ensuring that the special educational needs of children with autism are properly addressed within the educational system;*
- *Having regard to the range of special educational provision and support services already made available to children with autism in special schools, special classes attached to ordinary schools and in integrated settings;*
- *Having regard to the desirability of ensuring that the services made available to children with autism reflect best international practice.*

The Task Force on Autism will:

- Review the current range of educational provision and the support services available to children with autism in Ireland;*
- Assess the adequacy of current educational provision and support services, having regard to the range of special needs which can arise and the need to address such needs either in integrated settings or by way of special dedicated provision;*
- Make such recommendations as are considered appropriate for the development or adjustment of existing policy approaches, educational provision and support services, in order to ensure the delivery of an appropriate, effective and efficient education service to children with autism;*
- Make such further recommendations as the Task Force considers appropriate in relation to the above matters.*

1.3 SCOPE OF THE TERMS OF REFERENCE

With regard to defining the terms *autism* and *child* the Task Force decided that:

- i) it would interpret the word *autism* in the terms of reference as denoting *autistic spectrum disorders*;
- ii) an *education service* in respect of children *with autism* encompassed educational provision for persons with autistic spectrum disorders from the earliest age through to third level and continuing education.

In this Report *Autistic Disorder, Pervasive Developmental Disorders-Not Otherwise Specified (PDD-NOS), and Asperger's Syndrome or higher functioning autism (AS/HFA)* are referred to collectively as "*autistic spectrum disorders*" (see Chapter Two). The terms of reference were consequently interpreted as requiring that the Task Force address the wide range of special educational needs in the population of persons with autistic spectrum disorders (ASDs).

1.4 WORKING ARRANGEMENTS

Following an advertisement in October 2000, 108 written submissions were received from parents, service providers and other interested parties, including three from the United States and one from England. Copies of all submissions were circulated to members, a comprehensive analysis of the submissions was conducted, and extremely careful consideration was given to the submissions by the Task Force in drafting its Report. A list of those who made submissions is given in Appendix 2.

From its inauguration in October 2000 to the completion of its Report in November 2001, the Task Force held twenty meetings, a number of them extending over three days. As well as the meetings, the work involved the analysis of submissions, outlined above, a review of the international research literature on ASDs and educational interventions, a and review of existing educational provision for children with ASD and the subsequent writing of this Report.

Within the constraints of the time available, visits were made by Task Force members to a number of schools and centres in the Republic, in Northern Ireland and in England that cater for persons with autistic spectrum disorders. The purpose of the visits was to enhance members' understanding of actual existing provision and also to afford them an opportunity to listen at first hand to the views of those directly involved in service delivery.

In its consideration of international good practice for students with ASDs, the Task Force was greatly assisted by linkages established under international

agreements. During a visit to Ireland by Secretary Riley of the United States Department of Education in 2000, a meeting of the Task Force with leading experts from the United States was arranged. The following experts attended a meeting of the Task Force: Dr. Philip Strain, Ms. Martha Ziegler and Ms. Patricia Guard (see Appendix 3).

Arising from the Good Friday Agreement, a *Special Education Co-ordination Group*, comprising representatives of the Departments of Education, North and South was established. Both Departments have subsequently set up groups to examine issues relating to autism. A joint meeting of the Task Force on Autism was held with members of the Northern Ireland Task Force on Autism, chaired by Mr Martin Clarke. An officer of the respective Departments of Education in each jurisdiction is a member of both Task Forces.

1.4.1. Independence of the Task Force on Autism

While the Task Force on Autism was established, and its members appointed by the Minister for Education and Science, it was agreed at the very outset that its Report would be *entirely independent* of the Department of Education and Science. Throughout its work the Task Force has been autonomous in its deliberations. While the Task Force sincerely hopes that its analysis and recommendations will be adopted by the Departments of State, it acknowledges that these recommendations are independent of any Department. The analysis and recommendations are based upon four key principles:

1. school placements, supports and educational interventions should be based upon the needs of the child
2. educational interventions should be empirically defensible, flexible, and in line with international good practice
3. special education is a *service*, not a place
4. parents should be fully involved in any educational intervention.

The analysis and recommendations in this Report relate to educational provision for persons with ASDs which, until now, has been deficient in many ways and in which entitlement to service has been unclear. This has led in an unacceptably high number of cases to lack or gross inadequacies in delivery of service. The Task Force emphasises that, in such a context, this Report represents not an end but a beginning of reform of the system. After implementation, the structures and interventions proposed here should themselves be subject to evaluation and review on a regular basis.

1.4.2 Structure of the Report

The Task Force on Autism set out to fulfil its very broad Terms of Reference and to make recommendations for an appropriate, effective and efficient education service to children with autistic spectrum disorders. This wide-ranging task meant that the Report had to be comprehensive and, at times, quite technical. No section or Chapter in the Report stands in isolation from the others. It is therefore necessary to view the recommendations in a particular Chapter in the light of recommendations elsewhere in the Report. Cross-referencing occurs where appropriate. Some inevitable repetition occurs as a result. Some of the Appendices contain reference material which, in the view of the Task Force, might be valuable to parents or professionals. The analysis and recommendations in the Report are based on:

- Issues emerging from the submissions made to the Task Force;
- A review of existing Irish and international research on good practice concerning the education and support of persons with autistic spectrum disorders.
- Review of existing educational provision for children with ASDs;
- Detailed and extensive deliberations at Task Force meetings.

1.4.3 Outline of the Report

Chapter Two deals with definitions and the prevalence of autistic spectrum disorders;

Chapter Three gives particular consideration to the role of parents as partners in the education of their children with ASDs;

Chapter Four focuses on issues relating to the identification that a person may be on the autistic spectrum, and on referral and assessment procedures.

Chapter Five presents an outline of general issues affecting individuals on the autistic spectrum;

Chapter Six presents and reviews the principal educational interventions for children with ASDs;

Chapter Seven gives an outline of issues and interventions in early education for children with ASDs;

Chapter Eight considers and reviews the education of children with ASDs at primary level;

Chapter Nine considers and reviews the education of children with ASDs at second level;

Chapter Ten gives consideration to issues relating to third level and continuing education for persons with ASDs;

Chapter Eleven reflects on the difficulties associated with the current level and quality of clinical and support services in Ireland for children with ASDs and their families;

Chapter Twelve presents a review of issues relating to the education and training of teachers, other professionals and support workers for persons with ASDs;

Chapter Thirteen presents a national structure for the implementation of the Task Force's proposals for educational provision and support services for persons with ASDs in Ireland;

Chapter Fourteen presents an overview of constitutional and legal issues as they pertain to the education of persons with ASDs;

Chapter Fifteen consists of an outline and review of policy in relation to the education and support of persons with ASDs and other disabilities;

Chapter Sixteen examines the costs and economic benefits associated with educational intervention for persons with ASDs;

Chapter Seventeen presents an overview of the recommendations of the Task Force on Autism.

The list of **References** provides details on all publications and documents to which direct reference is made in the various Chapters. An extended **Bibliography** is also presented which includes details on the wider range of research and publications which informed the thinking of the Task Force. A total of 21 **Appendices** with material of relevance to the education and support of persons with ASDs is also presented.

CHAPTER 2

AUTISTIC SPECTRUM DISORDERS

2.1 Introduction

This chapter presents definitions for the range of disorders on the Autistic Spectrum. It also outlines the difficulties associated with establishing incidence rates in Ireland.

Autism was first described as Infantile Autism in 1943 by Dr. Leo Kanner, Johns Hopkins University. Dr. Kanner identified a unique group of children who failed to develop normal social relationships, were upset by changes in their environments and showed abnormalities in speech and language. Kanner did not furnish diagnostic criteria but offered descriptive case histories highlighting common characteristic features. In 1944 Dr. Hans Asperger, a Viennese paediatrician, presented a distinct syndrome which shares many of the characteristics noted by Kanner but generally includes average intellectual and structural language abilities.

The term Pervasive Developmental Disorder (PDD) was first used in the 1980s to describe a category of neurological disorders with symptoms which in each case included a narrow range of interests, a tendency towards repetitive activity and severe and pervasive impairments in social interaction, imaginative activity and communication skills.

The term 'autism' conjures up a stereotypical and narrow meaning to the uninformed who visualise seemingly inaccessible, withdrawn children. The focus also tends to rest on children, rarely including adults. From time to time also there are portrayals in the media of the 'autistic savant', perceived as the 'strange person' with extraordinary skills in calculations, music, memory, or drawing. While these images are partly true they fail to recognise the full range of variations seen, as autism is truly a spectrum disorder. Average to high intelligence and good structural language skills also commonly occur in socially active children and adults with autism, but are less well identified and publicised. The majority of affected children fall somewhere between the extremes of ability and disability.

Research and personal accounts written by adults with Asperger's Syndrome or High Functioning Autism (Williams, 1994; Holliday-Willey, 1999; Joliffe, Lansdown and Robinson, 1992; Grandin, 1995) have increased our understanding that all differences associated with ASDs are not necessarily deficiencies. Such accounts have become a valuable source of information and insight into the perspectives of people with autistic spectrum disorders.

Although personal accounts indicate that enormous support is needed to minimise the effects of autistic spectrum disorders, they also suggest that ‘autism’ is not something a person ‘has’, rather it is a way of describing the way that a person ‘is’:

Autism tries to stop me from being true to myself. Autism tries to rob me of a life, of friendship, of caring, of sharing, of showing interest, of using my intelligence, of being affected ... it tries to bury me alive ... I can control autism ... I will control it ... it will not control me (Williams, 1994, Conclusion).

If I could snap my fingers and be non-autistic, I would not- because then I wouldn't be me. Autism is part of who I am (Grandin, 1995, p. 16).

No matter the hardships, I do not wish for a cure to Asperger's Syndrome. What I wish for is a cure for the common ill that pervades too many lives; the ill that makes people compare themselves to a normal that is measured in terms of perfect and absolute standards, most of which are impossible for anyone to reach (Holliday-Willey, 1999, p. 9).

2.2 AUTISTIC SPECTRUM DISORDERS

The term Autistic Spectrum Disorders (ASDs) is used throughout this Report to denote *Autistic Disorder, Pervasive Developmental Disorders-Not Otherwise Specified (PDD-NOS) and Asperger's Syndrome* as set out in the *DSM-IV-TR* system. Two main classification systems are used by mental health professionals. These are *The International Statistical Classification of Diseases and Related Health Problems, Tenth Revision, 1994 (ICD-10)* and the *Diagnostic and Statistical Manual of Mental Disorders, American Psychiatric Association, Fourth Edition, Text Revision, 2000 (DSM-IV-TR)*. (See Appendices 4 and 5). Both classification systems take the modern view of autism that:

there is a spectrum of autistic conditions and that they are disorders of development, not 'psychoses' (Wing L. 1996, p. 23).

Pervasive Developmental Disorders are characterised by qualitative abnormalities in reciprocal social interaction and patterns of communication, and by restricted, stereotyped and repetitive repertoire of interests and activities (the triad of impairments). These disorders usually have an age of onset before three years although children with Asperger Syndrome typically present for assessment relatively late in development (Volkmar, Klin, Schultz, Pauls, & Cohen. 1996). Asperger Syndrome appears to have a later onset or at least tends to be recognized at a later stage (NICHCY, 1998) .

Five disorders are listed in the DSM-IV-TR system as Pervasive Developmental Disorders (PDDs). These are:

- i. Autistic Disorder
- ii. Asperger's Syndrome
- iii. Childhood Disintegrative Disorder (*not* an Autistic Disorder)
- iv. Rett's Disorder (*not* an Autistic Disorder)
- v. Pervasive Developmental Disorder - Not Otherwise Specified (PDD-NOS)

In this Report the term ASDs is used to refer collectively to numbers i), ii) and v) above, the degenerative disorders of Rett's Disorder or Childhood Disintegrative Disorder are not included. This is keeping with practice at the U.S. Department of Health and Human Services, Centers for Disease Control and Prevention.

2.2.1 Autistic Disorder

Autistic disorder (DSM-IV-TR) or childhood autism (ICD 10) has an onset before the age of three and shows evidence of a cluster of features including abnormal functioning in social interaction, communication, and imagination and thought as evidenced through restricted, repetitive behaviour which cannot be solely explained on the basis of low cognitive functioning. It is much more common in boys. Autistic disorder is also known as "*Kanner's Syndrome*". This report will at times refer to Kanner's or classic autism, to reflect the current criteria for autistic disorder, and to differentiate from those with Asperger's Syndrome, or High Functioning Autism, which will be identified as AS/HFA..

2.2.2 Asperger's Disorder (DSM-IV-TR) / Asperger's Syndrome (ICD-10)

While this disorder has an '*uncertain nosological validity*', it shows the same kind of qualitative abnormalities of reciprocal social interaction as autistic disorder does with a restricted, stereotyped, repetitive repertoire of interests and activities. In international diagnostic terms, the main difference from autistic disorder has been that there is no clinically significant delay or retardation in cognitive development or in language acquisition, e.g. '*single words used by age two years*' (DSM-IV-TR) . More importantly, persons with AS have communication difficulties (regardless of structural language skill). The pragmatic aspects of their language are affected as are all of the paralinguistic features of gestures, facial expressions, intonation meaning and even personal space regulation.

Gillberg & Gillberg's set of diagnostic criteria (1989) are also considered useful by some clinicians as they include the language impairments commonly seen in AS. (See Appendix 6). They include:

- social impairment including egocentricity;

- narrow interest;
- repetitive routines;
- speech and language peculiarities;
- non-verbal communication problems;
- motor clumsiness.

It is to be noted, however, that the Gillberg and Gillberg symptom sets for Asperger's Syndrome are significantly different from those specified in the ICD-10 and DSM-IV-TR systems.

The term 'high functioning autism' (HFA) is sometimes used interchangeably with Asperger's Syndrome. There is still an unresolved debate around this issue, with some believing it is the same disorder, while others cite qualitative differences. The term HFA is not used in either the *ICD-10* or the *DSM-IV-TR* classification systems.

Hans Asperger's pioneering paper published in German in 1944 is part of the classic literature of child psychiatry and a landmark in the development of the concept of autism. In a climate of continuing debate between experts regarding the difference between Asperger's Syndrome and high functioning autism, for now, we work on the premise that these two conditions are more alike than they are different. Many believe that there are important differences related to whether or not the individual is oriented towards people. That difference, however, is not well characterised by the current divisions within the classification systems.

2.2.3 Atypical Autism or Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS)

These conditions differ from autistic disorder and Asperger's syndrome in terms either of age of onset or of failure to fulfil the criteria for these two conditions. Thus there may be an onset after three years (rare) or more typically, there are insufficient observable symptoms in two of the three areas required for a diagnosis of autism or Asperger's syndrome. Nonetheless, the children present with some of the behaviours associated with one of these conditions to a severe and pervasive degree. Children with some autistic behaviours that are not attributable to some other medical condition, may be said to have PDD-NOS. There is some evidence, however, that PDD-NOS may be regarded as a milder form of autistic disorder.

This diagnostic category is used when there is a severe and pervasive impairment in the development of reciprocal social interaction associated with impairment in either verbal or non-verbal communication skills or with the presence of stereotyped behaviour, interests and activities, but not meeting the diagnostic criteria for specific pervasive developmental disorders, e.g. autistic disorder or Asperger's Syndrome. PDD-NOS includes atypical autism, i.e.

presentations that are characterised by atypical symptomatology, or sub-threshold symptomatology, or late onset, or all of these.

A much-needed move towards more clarity in diagnosis of ASDs is reflected in recent professional discussions. It is expected that subsequent revisions of diagnostic manuals will reflect the more refined understanding that is evolving over time.

There is a high incidence of ASDs in children and adults with Down Syndrome (perhaps up to ten per cent, Howlin, Wing and Gould, 1995). ASDs in this population are likely to be under-diagnosed and diagnosed at a late stage as some of the criteria may be attributed to the intellectual disability.

2.3 CHARACTERISTICS OF PERSONS WITH AUTISTIC SPECTRUM DISORDERS (ASDs)

An extremely wide range of individual differences is represented within this grouping, from individuals who also have a severe learning disability, to those with average and above average intelligence. All share the triad of difficulties in reciprocal social interaction, communication, and a lack of flexible thinking. ASDs impact on all areas of functioning and have significant implications throughout the lives of those affected across the entire ability range:

It must be remembered that autism is diagnosed by the existence of the full triad of impairments and the particular manifestation of the triad will vary among individuals. There are no behaviours per se that by their presence or absence indicate autistic spectrum disorders; it is the overall pattern and underlying difficulties that define autism (Jordan et al, 1998, p. 14).

Although international research and debate is ongoing, there is theoretical confusion regarding differential diagnosis particularly at the extreme ends of the intellectual range. This uncertainty regarding the boundaries, and extent of overlap between differing forms of autistic spectrum disorders, highlights the limitations of current knowledge and diagnostic systems. The pattern of developmental progress is also variable, as in a minority of cases, children diagnosed with autistic disorder in childhood, may develop a pattern of abilities and behaviour in adolescence/adulthood, that more accurately resembles that of Asperger's Syndrome/High Functioning Autism.

If I were two years old today, I would be diagnosed with classic Kanner's Syndrome, because I had delayed abnormal speech development. However, as an adult I would probably be diagnosed as having Asperger's Syndrome, because I can pass a simple theory of mind test and I have greater cognitive flexibility than a classic Kanner autistic (Grandin, 1995, p. 60).

Therefore, great caution must be taken when attributing a particular intellectual level (I.Q.) to any individual with an ASD. Due to the nature of the disability, it is very difficult to secure a valid cognitive assessment. Additionally, the profile of someone with an ASD is most often markedly uneven. Scatter within skills and concept areas will also be evident. Full Scale I.Q. scores cannot then be used as representative. Nor can it be said that because a student has an I.Q. score in the average range in one area, that their potential or current functioning is in the average range as the variation in skills tends to persist over time. There can also be a significant increase in an I.Q. score (over twenty points - see Chapter 9) following intensive intervention. Except for those children with a very low, flat profile, most children with an ASD will be well into their primary education before there can be confidence in an assessment of their cognitive functioning.

2.3.1 Impairments of Social Interaction

Wing & Gould (1979) characterise the impairments by grouping them into four main 'types':

- *the aloof;*
- *the passive;*
- *the active but odd; and*
- *the 'over formal', stilted group.*

These are not rigid categories and the person may move through them in the course of development. Those who are socially 'aloof' are the most common type. They are withdrawn, have poor eye contact, and shun social contact. They seem cut off, in a world of their own. Young children in this group appear to be indifferent to or alarmed by their peers. Children who start in one category may change over time (through development, education and/or experience) so that they then later better fit another pattern. It should be noted that these refer to overall characteristic personality traits and that a child (who may have been 'aloof' in the past) who has become more sociable and then goes through a period of withdrawal in his/her teens should not have this dismissed as a return to the previous aloofness. Rather this should be taken as a cause for concern, needing investigation and possible intervention, as with any other child. The passive group of adults and children who are the least common, may also have poor eye contact, and are likely to accept social attention from others as long as it is not too sudden or invasive, although they do not initiate or seek it. They usually have the least behaviour problems of any within autistic spectrum disorders although some become disturbed in behaviour in adolescence. The active but odd group of children and adults want social contact and try to initiate it, but often get it wrong and cannot work out the social rules and their variations according to context. The over formal, stilted pattern of behaviour is not seen until later adolescence and adult life. It develops in those who are the most able. This group tries very hard to behave well and cope by sticking rigidly to the rules

of social interaction. All of the different sub-groups display a clear lack of understanding of other people's thoughts and feelings.

Social interaction is hampered by a fundamental lack of social understanding. Social behaviours in those who are less able, when there is continuing avoidance of contact with others, can make integration difficult. The inability to engage in social play, and the difficulties encountered in forming enduring peer friendships persist despite efforts of the more able group to be accepted, to join in with others and to make friends. It is the desire for friendship, without the necessary social competence, which may lead to many difficulties, including the onset of psychiatric disorders for this group.

I did not know how to make friends, so I would stand there calling this girl every four-letter word that I knew... Eventually this girl would take to her feet and chase me for several blocks ... when she decided at least to ask me why I had tormented her so persistently for so long ... 'I wanted to be your friend', I blurted out furiously (Williams, 1992, p. 29).

2.3.2 Impairments in Communication

Impairments in verbal and non-verbal communication are both central and fundamental to autistic spectrum disorders. The verbal difficulties may include a delay in the development of language, comprehension difficulties (discrepancies between the use & understanding of language), literalness, poorly modulated intonation and delivery of speech, echolalia (echoing speech), unusual vocabulary, repetitive use of language.

Non-verbal difficulties include failure to empathise with others and to appropriately use and interpret social cues, body language and facial expressions. Gestures may be stiff, stilted or alternatively, far too dramatic or exaggerated. People with autistic spectrum disorders may exhibit many of these problems to a greater or lesser degree. As they grow older skills may emerge but often with impairments in timing and sequencing. The over-riding problem, for almost everyone, and at whatever linguistic level they function, is the lack of reciprocity in their language; their failure to engage in normal conversations and to listen to other people's point of view (Howlin, 1997). The person who fails to acquire any spoken language, and struggles with signs, is at least recognised as having a problem, and others may try hard to adjust, even though the real nature of the difficulties may not be understood. The child with good speech, however, is often misunderstood, with his/her difficulties being attributed to a behaviour problem, unless the nature of the communication problem in autistic spectrum disorders is appreciated.

2.3.3 Lack of Flexibility of Thinking and Behaviour

Deficits in social imagination and lack of flexibility in thinking and behaviour are characteristic of autistic spectrum disorders and typically manifest in the form of resistance to change, restricted, repetitive activities and routines and an obsessional, narrow range of interests. Symbolic play and joint attention skills are impaired in children with autistic spectrum disorders. A lack of 'shared attention' or difficulty participating in the activities or enjoyment of others has been highlighted as a particular deficit. There are also identified problems in planning, monitoring or reflecting on thoughts and behaviours and consequent problems with spontaneity and with impulse control. The underlying impairment affects the ability to share interests, have varied interests, adapt behaviour according to the situation, accept changes in rules & routines, true imaginative play with others and alone, accept other's point of view, generalise learning, use of inference and deduction, and the creative planning, initiating and organising of activities. Regardless of intellectual ability, individuals are seriously impaired in their ability to understand other people's beliefs, knowledge, emotions, desires, intentions or feelings. This ability to 'understand minds' and to attribute mental states to oneself and others (Baron-Cohen, 1995) or theory of mind, remains profoundly affected throughout life (Howlin, 1997).

The causes of ritualistic behaviours are complex. Environmental and developmental factors play an important role. The degree to which individuals are able to develop their social, communication and cognitive skills, can have considerable impact on the extent of obsessional behaviours in later life (Howlin, 1997).

Reality to an Autistic person is a confusing interacting mass of events, places, sounds and sights. There seems to be no clear boundaries, order or meaning to anything. A large part of my life is spent trying to work out the pattern behind everything. Set routines, times, particular routes and rituals all help to get order into an unbearably chaotic life. Trying to keep everything the same reduces some of the terrible fear (Jolliffe, Lansdown and Robinson, 1992.).

In brief, ASDs are characterised by a triad of impairments in:

- social relationships
- communication
- social imagination and thought, including restricted, repetitive and stereotyped patterns of behaviour and interests.

It is now recognised that ASDs are:

- spectrum disorders, i.e. occurring across a range of abilities with varying degrees of triad impairments
- neurological-developmental disorders
- found in all parts of the world and in all types of families

- not rare disorders.

2.4 PROGNOSIS IN AUTISTIC SPECTRUM DISORDERS

Good outcome is generally defined in terms of reaching full potential, and an appropriate level of independence and social competence through acceptance within society. Kanner (1973) noted great variation in outcome and found that many who had made the greatest progress had done so via their obsessional interests, as this led to the development of valuable work-related skills. Asperger's reports on cases where early obsessions led to later success in life include a professor of astronomy, mathematicians, technologists, and chemists (for annotated translation of Asperger's paper, see Frith, 1991). Outcome may be influenced by the presence of additional skills and interests as this provides opportunities which enable those with autistic spectrum disorders to find their own 'niche'. Kanner (1973), Eisenberg (1956) and Rutter (1983) all suggested that, adequate educational opportunities, and encouragement to develop skills that may lead to later acceptance, are critical. It would seem more profitable in the long-term for educational programmes to concentrate on those areas in which the person with autism already demonstrates potential competence, rather than focusing on areas of deficit (Howlin, 1997).

Fixations are powerful motivators. It is a mistake to try to stamp out fixations ... When I was in high school many of my teachers and psychologist wanted me to get rid of my fixation on cattle shutes ... I have made a successful career based on my fixation with cattle squeeze shutes. I have designed livestock handling systems for major ranches and meat companies all over the world (Grandin, 1995, p. 130).

Follow up studies have consistently identified three particular factors related to later prognosis: early language, the degree of intellectual impairment and education (Howlin, 1997). The studies of Lotter (1974; 1978) also noted the association of years of schooling and later outcome. Kanner (1973) noted that 'admission to hospital care, rather than a school placement was tantamount to a death sentence'. Gillberg & Steffenberg (1987) cite IQ and early communicative speech as the important prognostic indicators. The key variables include IQ, the severity of the autism, early language and communicative competence, gender and social understanding (Jordan, Jones and Murray, 1998). Ruble & Dalrymple (1996) suggest that as these variables tend to remain stable, it may be more productive to focus on factors which can be altered to suit the individual. They argue that:

Defining outcome as the relationship between an individual's challenges and strengths, environmental stressors and supports, and other's perceptions of competence and self-perceptions of quality of life is more likely to yield a better combination of predictor variables than simply measures of IQ and language. (p. 13)

The experience of parents and some professionals (Howlin, 1997; Morgan, 1996) indicate that considerable improvements can be made throughout adult life in the acquisition of new skills and the reduction of behaviours that are interpreted as challenging. The nature of the environment created for them, the opportunities offered and the degree of sensitivity of support appear to be significant factors as well as the strengths, interests and sensitivities of the person themselves (Jordan et al, 1998).

The literature indicates a pattern of life-long disorder, whereby individuals with an autistic spectrum disorder continue to be 'autistic' throughout their lives. As understanding of autistic spectrum disorders develops, it is likely that outcome will improve as a result of more appropriate interventions and support. 'Value' judgements in terms of how 'success,' or a 'good quality' of life, is defined will vary depending on whose perspective is taken, e.g. the individuals themselves, their parents, teachers, support workers, or psychologists (Jordan et al, 1998). The purpose of education and intervention should be to identify strategies, which enable this group to develop the skills needed to live, learn and function effectively within society, according to a set of social rules, which they often perceive to be of little value. 'Success' should not be equated with 'normalising' but rather with recognising the value of diversity. Social policies, and the values underpinning the educational system will have an influence on what treatment is considered 'effective' and from whose perspective (Jordan et al, 1998).

2.5 SPECIAL EDUCATIONAL NEEDS OF PERSONS WITH ASDs

Learning difficulties and autistic spectrum disorders often but by no means always occur together. Autistic spectrum disorders can be found at any level of ability from profoundly disabled up to average or higher. Considering the whole range of autistic spectrum disorders, including the type described by Asperger, Wing (1996) suggests that about one third have significant learning difficulties, the majority of those being severely or profoundly intellectually disabled. Others may have academic difficulties for reasons associated with the triad of impairments, or may have visual or auditory processing difficulties, i.e. specific learning disabilities. Children with an ASD are just as vulnerable to attention deficit disorders as the general population, and this should be considered when diagnosing and preparing an educational plan.

The autistic spectrum disorders are medically defined conditions and, as such, do not translate directly into special educational needs. Clearly, factors in addition to a clinical diagnosis of an autistic spectrum disorder will need to be included in determining the degree and nature of a person's special educational needs. The extent of autistic traits and characteristics vary across the spectrum of ability in ASDs, as autistic severity and intellectual ability form two separate dimensions. The severity of the ASD will, therefore, play a role, as will any additional difficulties, the nature of any compensatory abilities, the person's

experience and motivation to learn, and the nature and quality of the education provided in any particular setting. For all persons with an ASD, it is likely that they will have special needs, which will require additional and special educational provision to be made. Students with autistic spectrum disorders benefit in settings that are well-structured, task-oriented, with goals that are clear to teachers and students and offer individualised programmes (Rutter, 1983). This does not imply segregation, but it does require knowledge of the condition by the staff and environments in which the student is enabled to learn, whether in mainstream or specialist early services, primary, secondary, third level or continuing education.

People with autistic spectrum disorders lack an internal structure for their lives. They need to have an external framework constructed for them by those who care for them and teach them. Even those who are most able need this type of support. The most successful find it for themselves in the work and living arrangements they choose but even they are vulnerable if the structure is completely removed by the hazards of life (Wing, 1996. p. 91).

2.6 PREVALENCE

There are currently no reliable studies of prevalence that have covered autistic disorder *and* Asperger's Syndrome *and* pervasive developmental disorder not otherwise specified (PDD-NOS) in individuals in Ireland .

Efforts to estimate the prevalence of autistic spectrum disorders face a number of difficulties, including:

- lack of a biological marker or medical test as a basis for diagnosis;
- lack of full conformity between and specificity within the diagnostic systems in use;
- the extent to which periodic revisions in diagnostic systems, e.g. from DSM-III to DSM-IV-TR, affects the number of children to be included as having autistic spectrum disorders;
- confusion arising from imprecise use of the terms autism, autistic spectrum disorders, PDD, Asperger's Syndrome;
- lack of clarity amongst professionals not intimately familiar with the disorder, as to what criteria to apply during the diagnostic process;
- similarities with other disorders, e.g. language disorder & attention deficit hyperactivity disorder, particularly under three years old;

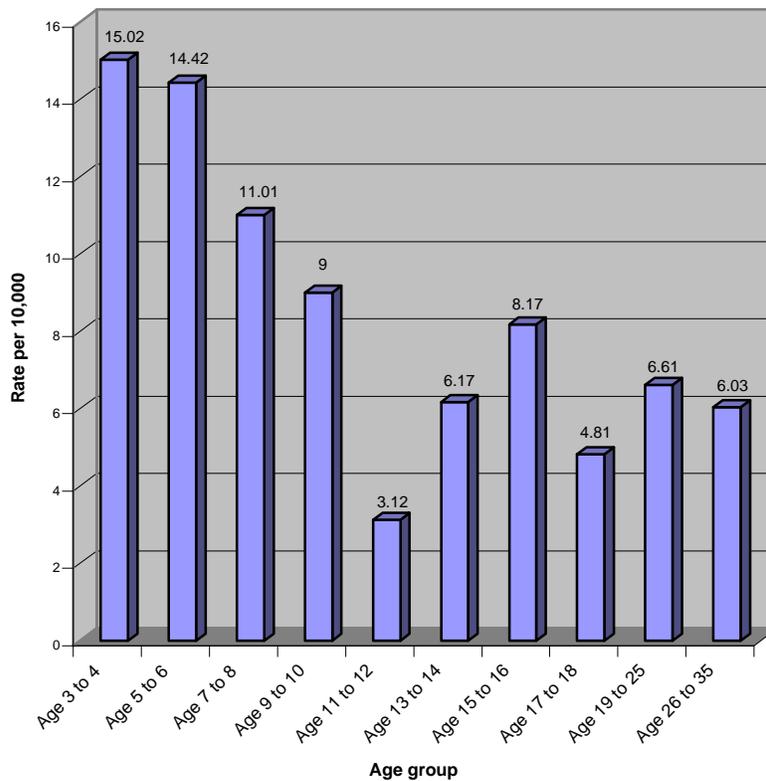
- misdiagnosis or lack of diagnosis for children and adults on the high end of the spectrum (Asperger's Syndrome/High Functioning Autism);
- variation between care-givers who provide information during the diagnostic process;
- hesitancy on the part of some professionals to make a specific diagnosis;
- absence of comprehensive screening and diagnostic procedures;
- lack of a comprehensive national system for recording and counting those with a diagnosis of an autistic spectrum disorder, i.e. a national database.

These problems are not unique to Ireland, but it has only been in very recent years that there has been an acknowledgement that the numbers of persons with an ASD is substantial. In this regard, we are notably behind such countries as the United Kingdom and the United States. It must, therefore, be acknowledged that estimates presented on current, incomplete data, are likely to be gross underestimates. This is particularly true for Asperger's Syndrome. Each new study reports higher incidence rates, confirming that diagnosis and, almost certainly, incidence is on the increase. The increase in the number diagnosed may be attributable to a variety of factors, including better diagnostic screening and possibly dietary and environmental factors. These, and other possible causes, are the subject of intense debate and require further research.

The general literature on autistic disorder cites estimates from epidemiological reviews ranging from 3 to 20 per 10,000. Few studies identify the rates for Asperger's Syndrome though figures from the most widely accepted studies indicate a rate of 36 per 10,000 (Ehlers and Gillberg, 1993; Fitzgerald, 1997). New research and prevalence studies are attempting to pin point where the increase in prevalence occurs. The California Health and Human Services Agency: Department of Developmental Services Report (1999) stated that it is the number of individuals without mental retardation (IQ Seventy +) that has risen most steeply. Honda et al, (1996) suggested that the increase in ASD prevalence rates were primarily at the cognitive extremes of the spectrum: the severely affected and to a greater extent, the more able children (Fombonne, 1998). In a more recent, comprehensive study, this same researcher (Chakrabarti and Fombonne, 2001) estimated the prevalence of children with a Pervasive Developmental Disorder to be 62.6 per 10,000. This is compatible with analysis of data collated in Northern Ireland (2001) by their Task Group on Autism, which reveals that over the next few years, the rate in Northern Ireland schools will rise to over 70 per 10,000. The increase in figures is attributed to the high proportion of children with PDD-NOS and Asperger Syndrome, who were likely excluded from the more narrow definition in earlier studies, and the only recent development of reliable and valid assessment tools for identifying persons at this end of the spectrum.

Fitzgerald, Matthews, Birkberk and O'Connor (1997) examined diagnostic, prevalence, psychosocial and service issues in relation to persons with autism in the Eastern Health Board area in the period 1990-1992. This study has since been updated and reprinted (Fitzgerald, Matthews, Birkberk and O'Connor, 2000). The Irish Society for Autism published a prevalence study specific to autistic disorder in conjunction with the Eastern Health Board (2001). Neither were designed to identify incidence rates, rather to 'count' the number of children already diagnosed with an autistic disorder and known to specialist services. Thus their figures are a starting point, but do not represent the prevalence of autistic disorder as many children are as yet undiagnosed. The first study was published in 1997 and found 272 (5 per 10,000) persons in the age-range 0-25 years who met diagnostic criteria for autistic disorder using the Autistic Disorders Diagnostic Checklist (Wing,1987). DSM-III-R and ICD-10 criteria gave a prevalence rate of 4-5 per 10,000. The 2001 study again counted only children at least three years of age who were already known to agencies. It emphasises that their numbers are 'certainly an underestimate'. The figure below is from the 2001 study and confirms that diagnosis of autistic disorder is on the increase.

Figure 1: Prevalence of those already Diagnosed with Autistic Disorder Irish Society for Autism & ERHA, 2001



They estimate that a more likely prevalence rate for autistic disorder is 'closer to 20 per 10,000 live births'. Given international reporting trends of increased incidence and/or diagnosis of autistic disorder, this rate appears reasonable but is also likely to be a low estimate. Furthermore, when Asperger's Syndrome is considered, a much greater number is expected as reflected in the figures below.

Based on the ISA/ERHA study cited above, and using a rate of 15 per 10,000 applied nationally, the Irish Society for Autism have estimated the number of children aged four and above and adults with autistic disorder in need of services to be 1,516. However, the ISA also states "with some certainty" that this survey of persons with autistic disorder is an underestimate of the true prevalence. They argue that, if the children awaiting diagnosis were factored into the equation, the true prevalence rate would be 20 per 10,000 for this category of the ASD spectrum. Taking 20/10,000 as the rate and applying it to the Irish population aged 0-19 years which, according to the most recent (1996) Census of Population figures (CSO, 2001) is 1,198,960, provides an estimated number of persons with autistic disorder in this age group of 2,398.

The Irish Society for Autism/Eastern Regional Health Authority study does not include any estimate of the prevalence of Asperger's Syndrome. A recent report on Asperger's Syndrome, conducted by the South Western Area Health Board (2001), points out that the prevalence of Asperger's Syndrome in Ireland is not yet known. The report also points (p. 5) to the urgent need to carry out research into the prevalence of Asperger's Syndrome in this country. It refers to international research on prevalence, in particular the Swedish research by Ehlers and Gillberg (1993) in which a prevalence of 36 per 10,000 was found. When this rate is applied to the 0-19 age group in Ireland, it provides an estimated figure of 4,316 persons with Asperger's Syndrome. Taken together, the upper estimates of prevalence of persons in two ASD categories (Kanner + Asperger's syndrome) in the 0-19 age-group give a figure of 6,714 in need of service. This figure would, of course, include students with very different levels of need and dependency.

It is, therefore, vital that the Departments of Health and Children, and Education and Science, agree a strategic rate for ASD to ensure that resources can be sufficient and fit for purpose. These prevalence estimates indicate that, as an initial target, provision should be made for services for some 20 per 10,000 with autistic disorder and for 36 per 10,000 with Asperger's syndrome.

Research information regarding PDD-NOS is relatively limited. As stated by Towbin (1994)

this partially reflects the continuing debate about the best approach to the diagnosis of conditions that appear to be related to autism as well as the difficulties obtaining research support for a very poorly defined condition. This condition is, however, probably much more common than the strictly

defined autism, requires rather similar kinds of treatment, and may, depending on associated developmental problems, have a better outcome than autism.

As no specific information is not available regarding the frequency with which PDD-NOS is diagnosed in Ireland, the Task Force proposes that the estimation of prevalence rates in respect of PDD-NOS should await the outcome of a research study.

2.7 Recommendations

The Task Force recommends:

1. as a matter of urgency, that research be conducted into the national prevalence of autistic disorder;
2. as a matter of urgency, that research be conducted into the national prevalence of Asperger's disorder;
3. as a matter of urgency, that research be conducted into the national prevalence of PDD-NOS;
4. that the Department of Education and Science and the Department of Health and Children establish compatible databases on children and adults who have a diagnosis of autistic disorder;
5. that the Department of Education and Science and the Department of Health and Children establish compatible databases on children and adults who have a diagnosis of Asperger's disorder;
6. that the Department of Education and Science and the Department of Health and Children establish compatible databases on children and adults who have a diagnosis of PDD-NOS;
7. until such time as national ASD data bases are fully operational, that the Department of Education and Science and the Department of Health and Children agree a prevalence rate for ASDs as a basis of forward planning for the provision of services. Prevalence estimates indicate that, as an initial target, provision be made for services for at least 20 per 10,000 with autistic disorder and for 36 per 10,000 with Asperger's Syndrome.

CHAPTER 3

PARENTS AS PARTNERS

3.0 INTRODUCTION

Autistic spectrum disorders enter the lives of families uninvited and unannounced. By their very nature, such disorders are initially unobserved, silent and hidden. There are no apparent signs at birth and there is no warning to alert parents to what lies ahead. Partnership between parents and their children with autistic spectrum disorders emerges gradually as a consequence of their evolving awareness of the vulnerability of the affected child. The roles of parents are shaped by culture and society. Definitions of partnership, and the practices arising from such definitions, vary a good deal between education systems (Conaty 1999). However, when a child has a disability, such as an autistic spectrum disorder, the need for a very specific form of partnership arises.

While the focus of the discussion in this Chapter is on parents as partners in the education of their children, the Task Force acknowledges that, in certain circumstances (e.g. due to bereavement or other factors), other family members or guardians may act *in loco parentis*. Clearly, the good practice in partnership identified later in this Chapter applies equally to circumstances where others act *in loco parentis*.

The diagnosis of an autistic spectrum disorder is a stressful and significant event in the lives of families. Such a diagnosis often follows years of uncertainty where parents struggle to cope with their child's 'difference' and try to rationalise behaviour that is unusual, unmanageable and often unresponsive to parental controls. The effects of working in isolation with a child/ young person who does not seem to understand or conform to the norms of social behaviour and communication are overwhelming. In Ireland, diagnosis of autistic spectrum disorders remain problematic, with significant delays being the norm in many instances, (see chapter 4). Although some children in Ireland are now diagnosed before or by the age of five, many high functioning children with Asperger's Syndrome are not diagnosed until adolescence or later. This delay is unsatisfactory and unacceptable.

Often by the time a definite diagnosis is secured, the initial response is one of sheer relief as:

- diagnosis removes the uncertainty and provides parents with a sense of empowerment as they approach decisions regarding the future;

- it offers parents the opportunity respond to their child in an informed and productive manner and to explore future options for the education and support of the child;
- it offers parents the opportunity to gain accurate information and to begin to understand the difficulties of their child;
- diagnosis gives parents the opportunity to network with other parents of children with autistic spectrum disorders.
- initially, parents expect to be relieved of carrying the sole responsibility for the welfare and appropriate support of their child;
- it encourages parents to seek the support of appropriately identified professionals and therapies;

Unfortunately, the relief is often short lived and may be followed by intense worry and stress, as the implications of having a child / young adult with an autistic spectrum disorder become apparent. New difficulties, which routinely exacerbate an already stressful situation, include:

- support services needed by the child are routinely difficult to access;
- therapeutic support is often unavailable;
- there is little outside understanding or acceptance of 'hidden' disability;
- parents realise they have unwittingly been delivered into a system which has failed to address the need for distinct provision across the range of abilities within the autistic spectrum;
- parents experience difficulties as they try to come to terms with the implications of life long disability;
- the realisation that every gain made in terms of accessing support will take intense effort, perseverance, determination and a considerable length of time.

Numerous submissions to the ATF refer to delays regarding diagnosis of an autistic spectrum disorder:

Many of our children were not diagnosed as having Asperger's Syndrome until the children had spent years in special schools or mainstream schools (or trying to get into same). Very often vital formative years had passed without diagnosis due to lack of resources or downright failure by the existing structures to recognise and diagnose the problem.

Similarly:

As you can see, E. had no service for the first seven years of his life. No words could express the worry, anxiety, and hardship that we as a family experienced during these years ... I am extremely concerned about E. at the present time ...

The evidence to the Task Force strongly confirms the view expressed by Warnock in 1978 (below), and endorses the Task Force's belief that initiatives to promote the education and well-being of children and young

persons with autistic spectrum disorders can only be effective when there exists a partnership, an equal partnership, between parents and professionals.

We have insisted throughout this report that the successful education of children with special educational needs is dependent upon the full involvement of their parents: indeed, unless the parents are seen as equal partners in the educational process the purpose of our report will be frustrated (Warnock, 1978 p. 150).

Partnership between parents and professionals is central to the success of all intervention, education and support for children and young persons with autistic spectrum disorders and indicates the need for mutual collaboration, co-operation, inter-dependence, and respect in the pursuit of common aims and goals. Children and young persons with autistic spectrum disorders need continuity of approach provided by parents and professionals working together from the beginning, to meet the challenges presented by this group. Yet, despite the best efforts of both parents and professionals, partnerships are often fragile. It is, therefore, important to acknowledge that parents and professionals are likely to approach their working relationships from equally valid, but fundamentally different, perspectives. The relationship between professionals and parents is unbalanced from the start (Brynelsen, 1984).

Professionals choose their careers, and have a formal training in preparation for their work. They are expected to be knowledgeable and are paid (more or less) accordingly. These are factors, which give power to professionals that parents do not have. Parents do not choose to have a child / adult with special needs, and they do not have a formal training to prepare them. The rewards are not monetary; they are intangible. Parents have limited choices and may experience difficulty in gaining the information they need (McConachie, 1994. p.74).

There is abundant evidence from the submissions to the Task Force to highlight the stressful experiences of families of children and young persons with autistic spectrum disorders. Much of the evidence is a disturbing reflection of the statutory agencies responses to the plight of parents seeking advice, practical support and appropriate intervention for their children. The concept of partnership between the parents of children with disabilities such as those on the autistic spectrum and professionals has not been explored or considered sufficiently; this Report asserts the belief that such partnerships are crucial and complementary. A submission to the Task Force refers to the difficulties experienced by parents;

Parents are not always aware of their choices, or of the advantages/disadvantages of recommended placements in the context of the changing needs of their AS/HFA children throughout their educational lives. The reality is that parents often have little real input regarding the appropriate options for the education of their children as provision of support seldom reflects need.

Similarly, a parent explains that:

I have spent my life trying to find a place for him in our educational system. It must be appreciated how different children with autism are from each other and no one recipe will work for all children simply because they have a diagnosis of autism /Asperger's ...

Another parent refers to lack of interdepartmental collaboration between the Departments of Health and Children, and Education and Science:

The burden should not be on parents to shuttle between these two departments, neither of whom takes exclusive responsibility for the provision of adequate services for people with Autism.

3.1 THE CURRENT POSITION

The Constitution of Ireland (Article 41) places an obligation on the State and its Government Departments to recognise the Family as the natural primary and fundamental unit group of Society, and as a moral institution possessing inalienable and imprescriptible rights. It guarantees to protect the Family in its institution and authority, as the necessary basis of social order. The Constitution (Article 42) also places an obligation on the State to acknowledge parents and the family as the primary and natural educators of the child and guarantees to respect the rights and duties of parents in this regard. European models for the provision of services for persons with disabilities are gradually moving towards flexible, evidence based, energetic and individual centred provision. Social policy, which stresses inclusion as a leading policy target and promotes principles of equality, mainstreaming, consumer participation, advocacy, accountability, quality of provision and the adoption of rights based, rather than a welfare based approach to disability, has enhanced recognition of the role of parents as partners in disability issues and has, in theory, paved the way for new, inclusive and enlightened thinking.

3.1.1 The National Parents Councils (Primary and Post Primary)

The National Parents Councils, Primary and Post Primary, were established in 1985. The Councils have the same rights to consultation as the Management and Teachers unions and are recognised in the 1998 Education Act.

3.1.1.1 The National Parents Council-Primary

The National Parents Council-Primary negotiates with the Minister and Department of Education for improvements in the education system and

better resources for primary education. The Council represents parent's views on education - including curriculum, class size, and school transport. The Council works for the rights and entitlements of all children and particularly children with special needs through the work of the Integrated Education Group (IEG). The barriers experienced by parents as partners in education are emphasised by the following observations;

While partnership in education at national level is well developed by national standards, partnership at school level still has ground to make up. There is an entrenched attitude of resistance to parental involvement at some levels and in some circles. The right of parents and children to give their views on the quality of schools as a part of Whole Schools Evaluation is a fundamental issue which cannot continue to be ignored. There is a lack of will to address the issue of poor teaching, in a supportive way. The school year continues to be eroded. There is an ongoing problem of lack of access to information about education, or any say in local decisions due to the highly centralised nature of Irish education. There are poor connections between the education services and other services, to the detriment of children. There are ongoing challenges facing parents of children with special needs. Some of these problems will only be resolved in the context of significant structural and cultural change (National Parents' Council-Primary, Annual Report, 2000. p.2).

3.1.1.2 National Parents Council – Primary: Integrated Education Group

The Integrated Education Group is a representative group for parents of children with Special Needs attending mainstream schools. Parents who have children with Special Needs attending mainstream schools can become members of the group. However, all parents who have an interest in the education of children with Special Needs are encouraged to make contact with, get information from or submit their views to the group. Parent Associations (PA) in mainstream primary schools that have children with special needs attending may each nominate an Integration group delegate. The Integration Group delegates in each county collectively form a County Integration Group, which select one person to represent them on the National Integration Group. Two members of this group are then selected to serve on the National Executive of the Council <http://www.npc.ie/> .

3.1.1.3 National Parents Council – Primary: Special Education Group

The Special Education Group of the National Parents Council - Primary believes that all children with Special Education Needs have a right to education which is appropriate to their individual needs and circumstances; that the State provides and develops Special Education for all children with Special Education Needs which are specialised, innovative, of high quality

and well resourced; to continually seek to improve and provide a model of good practice. The group has two parent representatives on the National Executive. Their aims and objectives include;

- To provide parents of children attending special schools, special classes and mainstream schools, a means for expression of their individual and collective opinions on matters affecting the education of their children with special education needs.
- To acknowledge the individuality, potential and worth of each child and take into account the individual child's learning needs.
- To encourage and facilitate partnership with parents, children, families, other groups and other professionals engaged in the education of children with special education needs.
- To arrange or assist in arranging and providing conferences, discussions and meetings on subjects of general or special interest in the field of special education.
- To recognise the difficulties that families face in living with a child with a disability and to enable a range of opportunities for contact and support in an open and sensitive manner.
- To actively participate in the consultation, planning and monitoring process to establish further education and training facilities and relevant services for their children when they become adults.
- To provide a forum for Parents, Teachers, other professionals, carers, siblings, the child where possible and any other relevant group or body to come together to serve the best interests of the child with special education needs.

3.1.1.4 National Parents Council - Post Primary

National Parents Council - Post Primary is a voluntary group, which has a board of 18 members who work on behalf of parents and children without remuneration. National Parents Council - Post Primary is the umbrella group for parent associations in the second level sector of the Irish education system. Initially, the Department of Education and Science wanted the second level Parents' Council to be similar in structure to the primary Parents' Council. This proved unacceptable to the parents' groups, as it was felt that some types of schools already had Parents associations set up on a National basis which represented their particular interests and that an umbrella group with delegates selected by the Associations would work best (National Parents' Council – Post Primary, <http://www.edunet.ie/parents/Welcome.html>). The secondary system contains three principal school types; voluntary secondary schools, vocational schools and colleges, and community and comprehensive schools (Drudy and Lynch, 1993). The vocational schools/colleges sector and the community/comprehensive school sector each has their National Parents' associations. The voluntary secondary school sector has three National

Parents' associations for different sub-sets of schools. These five national groups were formed into National Parents Council post primary to facilitate a more united form of communication with the Department of Education. The original role was to give a united voice to the parents, through their constituent bodies, in the second level system. Currently the Council represents parents on much more than education committees. They are involved in areas which include:

- Health;
- Underage drinking;
- Children's rights;
- Special needs;
- Garda youth advisory committee;
- Anti-poverty;
- Anti-drug committees;
- County Development Boards.

The Council note that;

To be seriously involved in a way that parents should be requires a substantial financial commitment; this is not in place at the moment. The current level of funding allows a token involvement for parents but does not address the development of working parent groups at school level. It also fails to enable training and research, a necessary part of being a full partner in any system <http://www.npcpp.ie/>.

The Aims and Objectives of the Council include:

- the promotion and protection of the role of the parent as the primary educator of his/her children;
- to involve parents actively in all aspects of the education of their children;
- to provide an effective voice for parents in the development of an elected parents group in each school;
- to monitor educational development and educational opportunities.

The Task Force charges the government with the continued responsibility of validating the stated aims whilst promoting the role of parents of children and young persons with autistic spectrum disorders as full and equal partners.

3.1.2 The Education Act, 1998

The Education Act provides (Section 6) that one of the objects of the Act will be to give practical effect to the constitutional rights of children, including children with a disability or other special educational needs. The Act also requires (Section 7) the Minister, wherever practicable, to consult with persons representing people with disabilities and other special educational needs. The Minister will have to ensure that there is made available to each person, including those with a disability or other special educational needs, an appropriate level and quality of education and appropriate support services. The Act gives statutory recognition to the National Parents Councils and states that:

- Parents will have a statutory right to establish parents' associations in schools. Parent representatives will have a statutory right to participation in boards of management, including deciding on their membership;
- Parents will be entitled to receive copies of any reports on the operation and performance of the school produced by the board of management and will have access to the school accounts on the same basis as the Minister. They will be involved in the preparation of the school plan, copies of which will also be circulated to them;
- Parents will have a right of access to their children's school records;
- Parents will be consulted in relation to the assessment of the psychological needs of their children and will be advised by the psychologists concerned in relation to the education and psychological development of the children;
- Parents will have the right to appeal to the board of management against a decision of a teacher or member of staff of the school and to the Secretary General of the Department of Education and Science against certain actions taken by the board of management;
- Students aged eighteen or over will have a right of access to their own school records. They will also have the right to appeal to the board of management against a decision of a teacher or member of staff of the school and to the Secretary General of the Department of Education and Science against certain actions taken by the board of management. Finally, they will not be obliged to attend instruction in any subject contrary to their conscience. The rights of students who are younger than 18 will, in respect of these matters, be exercised by their parents.

The Task Force endorses the Education Act, 1998 while nevertheless acknowledging the need for a civil rights statute to deal with the educational rights of persons with disabilities (see chapter 14).

3.1.3 The Freedom of Information Act, 1997

The *Freedom of Information Act 1997* asserts the right of members of the public to obtain access to official information to the greatest extent possible consistent with the public interest and the right to privacy of individuals.

The Act establishes three new statutory rights:

- a legal right for each person to access information held by public bodies;
- a legal right for each person to have official information relating to him/herself amended where it is incomplete, incorrect or misleading;
- a legal right for each person to obtain reasons for decisions affecting him/herself.

The Task Force recognises the importance of this Act and urges that it is invoked, where appropriate, to the benefit of children and young persons with autistic spectrum disorders and their families.

3.1.4 The Report of the Commission on the Status of People with Disabilities (1996)

The Recommendations of the Report of the Commission on the Status of People with Disabilities (1996) regarding the roles, responsibilities and rights of parents to participate as full and equal partners in the education of their children with disabilities, state that:

I. *Parents have primacy in the decision making process as soon as their child has been identified as having particular educational needs. They (and the child whenever appropriate) must be entitled to make an informed choice on the educational placement of their child* (11.8, principle 5).

II. *The legal rights, roles and responsibilities of parents must be clearly outlined in relation to any assessment or decision making process and should reflect the constitutional rights of parents in the matter of the child's education* (11.14).

III. *Parents must be acknowledged as full and equal partners throughout the educational process and be provided with guidance and support, full information about their child's progress, and be allowed to contribute meaningfully to it* (11.19).

IV. *Consultation with people with disabilities and their representative organisations must be a key feature of future policy formation ...* (11.20).

The Report further identifies common barriers to users who try to get involved:

- Professional barriers: a reluctance on the part of providers to risk abandoning 'expert' roles and boundaries in order to involve people with disabilities as equal partners
- Complex organisational systems and hierarchies that make it difficult for users to find a way into participation and involvement
- Decision making bound up in bureaucracy which is not responsive to new ideas and information
- Organisational confusion about involving people with disabilities – who to involve? How to involve them?
- Initiatives that involve people with disabilities in planning meetings but then fail to follow up with feedback or the implementation of recommended changes and thus break off a potential on-going dialogue
- Initiatives that only involve some types of service users while overlooking others or assuming that they cannot know what is best for them'. (Section 3.37)

This report of the Commission on the status of People with Disabilities represents a significant landmark in that it establishes recognition of the roles, rights and responsibilities of persons with disabilities, their parents and their representative organisations.

3.1.5 The Home/School/Community Liaison Scheme

The Home/School Community Liaison Scheme was established in 1990 by the Department of Education & Science with the assistance of the European Social Fund as a preventative strategy targeted at students at risk of not reaching their potential in the education system in large urban disadvantaged areas. A National Co-ordinator and an Assistant Co-ordinator advise on, and support the development of the scheme, liaise with participants in the scheme at local level and provide a link between local and national levels. Currently, some 166 co-ordinators serving 276 schools at primary level and 180 co-ordinators serving 179 schools at secondary-level deliver the scheme. The aims of the scheme include:

- To maximise participation of the children in the scheme schools in the learning process, in particular those who might be at risk of failure;
- To promote active co-operation between home, school and relevant community agencies in promoting the educational interests of the children;
- To raise awareness in parents of their own capacities to enhance their children's educational progress and to assist them in developing relevant skills;
- To enhance children's uptake from education, their retention in the educational system, their continuation to post-compulsory and third level education, and their attitudes to life-long learning;

- To disseminate the positive outcomes of the scheme throughout the school system generally.

While the focus of the Home/School/Community Liaison Scheme is directed to socio-economic disadvantage, it provides a valuable model of partnership which could be adapted to the needs of persons with ASDs and other disabilities, and their families. The basic principles of the scheme imply the sharing of information, responsibility, skills, decision-making and accountability. The scheme consists of a partnership and collaboration of the complementary skills of parents and teachers.

3.1.6 Further Recent Developments

Recent developments, which are indicative of positive change in the way in which disability issues and partnerships will be viewed in the future include:

- The establishment of the National Disability Authority, (see Appendix 18, par. 8).
- The Equal Status Act 2000, (albeit with limitations : see chapter 14 and appendix 18, par.9).
- The setting up of a Human Rights Commission (2000) (see Appendix 18, par. 11).
- The decision as the last of the 41 Member States of the Council of Europe to incorporate the European Convention into Irish Law. (see Appendix 18, par. 13).

3.1.7 Parent Organisations/Voluntary Associations

Autistic disorder/Asperger's Syndrome organisations are often the main source of information and support for children and young persons with autistic spectrum disorders and their families. They fulfil a significant role, which should be acknowledged and encouraged (SWAHB, 2001). Support networks of this nature empower persons with autistic spectrum disorders and their parents to make informed and positive choices, and provide a forum, through which they have the opportunity to express their common views and needs with a collective voice. The number of voluntary disability organisations has increased greatly in the last decade, which suggests either that there is a widening of the range of services being provided by them or that organisations are now more forthright about acknowledging the importance of services such as information and advocacy (Dolan, 2000). This increase also serves to highlight the shift towards meaningful 'consumer participation' and indicates that future policy and provision will be informed not only by the perspectives of service providers, but also by the perspective of consumers. Parents and their representative organisations have worked diligently on behalf of children and young persons with autistic spectrum disorders. They have as a result, become a vibrant force in all aspects of the disability movement, as they increasingly recognise, assert and exercise their

natural right to parity of esteem as full and equal partners at all levels of policy, planning and delivery of services for their children. A submission to the Task Force states that:

...An effective forum must have parents, not just one father and one mother, but a good selection of parents. Parents of autistic persons in Ireland work at the 'coal face'. Many have had to develop an expertise far beyond what should have been required. Parents have the motivation not just of professionalism but of love and necessity to ensure that the recommendations of a real forum are adequate and implemented.

The Task Force views representative organisations for children and persons with autistic spectrum disorders as a strong element of effective partnership arrangements and regard such organisations as key players in the formulation of policy, the promotion of effective planning and the provision of appropriate services for such persons. The Task Force places on record the need to create a national autistic spectrum disorder forum to facilitate the exchange of information, views and actions between representative organisations and relevant state bodies.

3.2 TOWARDS PARTNERSHIP

Although considerable progress has been initiated in the wider theoretical recognition of parents as partners in disability issues, barriers remain in practice, and significant shortcomings and obstacles continue to hinder full parental inclusion in the consultative process and the development of partnerships. Parents have a right to make informed decisions in all matters concerning the well being of their children. Parental input should drive the decision making process throughout each stage of deliberations. Most parents are enthusiastic, have total commitment and are motivated to develop their child to his/her full potential. They expect that professionals will approach service delivery with the same commitment and they expect to be part of that process. The entitlements of parents will, therefore, need to be acknowledged.

There are many concerns outstanding, one of which is the reported practice whereby decisions are routinely made during the early part of meetings/case conferences before parents are invited to join health or education teams for the final stages of such meetings. Parents should be informed of their entitlement to attend all meetings and case conferences concerning their children. They should be encouraged and invited to attend all such meetings where the progress or intervention of their child may be under deliberation. Advance notice of such meetings should be supplied to parents to facilitate the necessary arrangements, in order for parents to attend.

Parents must have right of access to all information regarding the case history of their child covering such matters as educational programmes, psychological testing, individualised assessments and other relevant

information. They must be involved in a full and meaningful way in the placement of their children whether in mainstream schools, special schools or residential centres of any kind.

There is a need for the creation of a national autistic spectrum disorder forum to facilitate the dissemination of information and the exchange of views between parents and professionals:

Parent's perceptions of the most valued qualities of services reflect a desire for parental involvement, consistency, co-ordination and accessibility, as much as for professional expertise, and these qualities reflect parents' need for some control in all the confusion (Rosenbaum, King and Cadman., 1992, p.103-114).

The ongoing need for enhanced collaboration and partnership with parents is becoming increasingly evident as families resort to the High Court to settle disputes, which arise regarding the provision of special education for children/adults with special educational needs. The High Court in recent years has exerted a very considerable influence over individual provision and policy in relation to special education.

With regard to state education and care services , Mr. Justice Barr stated in his judgement in the Jamie Sinnott case:

The history of Mrs. Sinnott's efforts for upwards of twenty years to obtain education and care for Jamie and others seriously afflicted with autism and related symptoms is a very depressing story with many disappointments and set-backs arising out of failure on the part of officialdom to address the problem of autism and how it should be treated – notwithstanding substantial international progress in that area since the 1960's and earlier which is well-known and documented. The evidence of a senior administrator in the Department of Education who has particular responsibility in the area under review, underlines the depth of ignorance of autism and its problems at official level. In Jamie's case the difficulty was aggravated by actual professional misinformation on how he should be treated which contributed to setting back his education and training for years.

Justice Barr also found that the State's breach of duty included (but was not restricted to) the following:

- *Failure to devise and operate a viable programme for Jamie's education and to do so in consultation with his mother.*
- *Failure to keep his mother adequately informed of her son's progress and of intended plans for his education and training.*
- *Failure to collaborate with his mother in devising a plan for his education and training.*

- *Failure to establish and maintain reasonable co-ordination between the ... (agency)and Mrs. Sinnott.*

The mother of a sixteen year old girl diagnosed with Asperger's Syndrome, whose case came recently before the High Court, highlighted the plight of persons with AS/HFA in a submission to the Task Force:

They are often referred to as the more `able` end of the Autistic Spectrum. ... Therefore they are capable of understanding that they are different, are much more conscious and aware of being ridiculed, socially isolated and rejected, I just can't understand how an average I.Q. can be such a disadvantage when trying to receive a suitable level of education...

Similarly, another parent states that:

We shouldn't have to beg, plead, and litigate to have his needs met.

3.2.1 Parents as Educators and Co-Therapists

The rights of the family as the primary and natural educator of the child, and as the primary unit group of society are enshrined in the Constitution of Ireland. Such rights convey not only entitlement, but also parental choice in the decision making process regarding all aspects of education and intervention for their children. It is now widely recognised that the co-operation and confidence of parents is crucial to the success of all intervention undertaken by teachers, clinicians and therapists, as students are influenced tremendously by parental attitudes and belief systems. Often, it takes only a glance or one word from a parent to endorse or reject the efforts of those involved in the delivery of education and intervention.

The Task Force acknowledges, naturally, that parents and families vary in their capacities to cope with the stresses and pressures of family life, especially if there are particular difficulties, such as a disability. The Task Force strongly recommends support for such families but also asserts that the State has obligations to persons with autistic spectrum disorders, as citizens, in instances where family breakdown occurs, or where the person with an ASD is unsupported due to bereavement. However, in the vast majority of circumstances, there are compelling reasons for recognising the potential benefits that the contribution of parents/guardians can make in terms of identifying and meeting the educational needs of those with ASDs:

- a) Parents are the primary educators of their children;
- b) the family is the primary agent of socialisation within society;
- c) parents are a valuable source of information regarding the individual needs of their children;
- d) the co-operation and confidence of parents is essential in all intervention undertaken by teachers, clinicians and therapists, as

children are influenced tremendously by parental attitudes and belief systems;

- e) to ensure consistency and continuity of approach between home and school;
- f) to facilitate accurate understanding of the child's actual needs, likes and dislikes, which may alleviate many behavioural difficulties, and in turn, reduce anxiety;
- g) to reduce the incidence of bullying through regular home/school liaison;
- h) because persons involved in the support of children with ASDs should have effective communication skills if they are to have any degree of success in imparting such skills to children/adults who have a deficit in this area;
- i) to increase the social opportunities for the child by facilitating parents need to 'help' their children/adults with autistic spectrum disorders.
- j) because, in practice, many parents (by default) are the primary 'service providers' for their children/adults with autistic spectrum disorders throughout their entire lives;
- k) to pre-empt or negate misunderstandings between home and school that may arise when pupils have communication difficulties and when behaviour may be very different in each setting.

The Report of the Working Group on Asperger's Syndrome (SWAHB, 2001) stresses the need for a partnership approach to intervention and recommends that parent support and the use of parents as co-therapists should be a central component of any treatment plan for those with AS/HFA. While information on the educational implications of ASDs undoubtedly needs to be disseminated not only to parents but also to relevant professionals working in the area of ASDs, there is also a need to ensure that the vast accumulation of experiential knowledge of parents is utilised to inform educational policy and practice. Many of the most respected approaches e.g. Applied Behaviour Analysis (ABA), Treatment and Education of Autistic and related Communications Handicapped Children (TEACCH), The Hanen Programme and The Portage Project, recognise and emphasise the role of parents as co-therapists in the successful implementation of their programmes:

..... parents have spent the most time with their children. They usually know them best and also have the highest motivation for developing the best possible family adjustment even when they have difficulty managing the child..... They also have the most extensive information for distinguishing the teaching techniques that worked for them from those that were ineffective. Moreover, effective help cannot be given without knowing family priorities, concerns and expectations.... (Schopler and Mesibov, 1984, p. 75).

When a child has a behaviour problem the whole family is brought under stress. However, the parents themselves are usually ideally situated to be their own children's therapists (Seheult, 1985, p. 40).

3.2.2 Parent - School Partnership

It is the belief of the Task Force that many persons with autistic spectrum disorders are at risk of not reaching their potential and are disadvantaged within the education system. Certainly any person with an ASD (and their parents) would greatly benefit from the establishment of a parent- school partnership scheme.

Throughout this report, the absolute necessity of including and supporting parents each step along the way has been emphasised. To facilitate this from the school level, a link person (facilitator) between home and school would be of great benefit to all involved in the education of the person with an ASD. The Task Force therefore recommends that each school with one or more ASD students be assigned a Department of Education and Science home-school Partnership Facilitator (PF) who would be based in the office of the Special Needs Organiser (recommended in the *Report of the Planning Group: A National Support Service for Special Education for Students with Disabilities, 2000*), but who would spend a majority of their time in their assigned schools. Their primary allegiance would be to advocate for the persons with ASDs. She/he would ensure good two-way communication between school and home. She/he would be in frequent liaison with the teachers (mainstream and special needs) and classroom assistants, school principal, Visiting Teacher for ASDs (recommended in Chapter 5), visiting clinicians, and any other support personnel involved in the school. She/he would facilitate parental involvement in relevant school activities and affairs, and ensure that information on the student's educational and social process is clearly co-ordinated with and transmitted to the family. She/he would engage in home visits as requested by parents, and phone contact, and so be in a position to relay back to school staff relevant non-confidential information on the child's home progress and circumstances, and any requests the parent may have. At the parent's request, she/he would make him/herself available to support the parent at school meetings and in any school-related decision-making process. She/he would be a key person in assisting the person with an ASD, his/her family, and the receiving school/ education institute when the person with an ASD is making the transition to another school/level of the educational system.

As students with an ASD will be relatively few in number in any one location, a ratio of students to Partnership Facilitator (PF) should be established. A ratio of 1:40 maximum could be used as an initial guideline, with limits placed on the geographical location of the schools and children's homes to ensure efficiency. The PF would have their office in the building of the Special Needs Organiser (or, pending the establishment of that Office, in one of the schools), but would be supporting a designated and limited number of schools in the region to facilitate schools with classes for children with an ASD, as well as those who may have one or two ASD students in the mainstream. Flexibility in work hours would be required to accommodate home visits. Policies and procedures would need to be developed to ensure the co-operation of any school educating a student with an ASD. Training packages would need to be developed and delivered for all involved for the programme to be successful. The DES Home/School/Community Liaison programme should be referenced

when establishing this new Parent - School Partnership arrangement for schools where there is a child with an ASD.

In conclusion, this Chapter sharply focuses on promotion of the role of parents and the voluntary organisations, which represent them collectively, as partners in the support of their children/young adults with an autistic spectrum disorder. It is the Task Force's belief that professional support cannot be wholly effective unless it stems from the parent's contribution as integral to intervention and development.

3.3. Recommendations

The Task Force recommends:

1. that the following principle and recommendations from the *Report of the Commission on the Status of People with Disabilities* (1996) be implemented without further delay and be incorporated in the forthcoming *Education (Disability and Training) Bill*:

Parents have primacy in the decision making process as soon as their child has been identified as having particular educational needs. They [and the child whenever appropriate] must be entitled to make an informed choice on the educational placement of their child, (11.8, principle 5, p.173).

....The legal rights, roles and responsibilities of parents must be clearly outlined in relation to any assessment or decision making process and should reflect the constitutional rights of parents in the matter of the child's education (par 11.14, p.175).

....Parents must be acknowledged as full and equal partners throughout the educational process and be provided with guidance and support, full information about their child's progress, and be allowed to contribute meaningfully to it (par 11.19, p. 176).

Consultation with people with disabilities and their representative organisations must be a key feature of future policy formation ... (par 11.20, p. 176);

2. that the role of parents as advocates for their children/young adults with autistic spectrum disorders be formally recognised;
3. that structures be established to ensure that the provision of support services and therapies, which are the responsibility of the Department of Health through the health boards, are delivered smoothly and seamlessly;

4. that a national forum for autistic spectrum disorder be established to facilitate the dissemination of information and exchange of views between parents, professionals and government departments;
5. that the Department of Education & Science initiate a Parent-School Partnership Scheme for persons with autistic spectrum disorders; that this entail the creation of Partnership Facilitator posts;
6. that consultation, collaboration and the inclusion of parent representatives/ voluntary and support organisations on Education, Health, Vocational Training and Supported Employment policy/planning teams and committees at local and national level be recognised as a key feature of future policy formation for ASDs; that professional input and training be provided to such parent representatives/organisations as appropriate;
7. that persons with Asperger's Syndrome/High functioning autism have the opportunity and be actively encouraged to participate on health/education planning committees;
8. that parents be informed of their entitlement to attend all meetings and case conferences concerning their children, including those where the progress or intervention of their child may be under deliberation; that advance notice of such meetings be supplied to parents to facilitate attendance;
9. that emphasis be placed on the centrality of parents in decision making relating to their child with an ASD.

CHAPTER 4

IDENTIFICATION, REFERRAL AND INITIAL ASSESSMENT

This section focuses on the difficulties specific to the clear identification of a set of problems as indicating an individual being on the autistic spectrum, the tools available to assist in this identification, how children may be identified as having an ASD, various routes to diagnosis, and the assessment process. Finally, the procedures the Task Force would like to see in place will be delineated. Throughout, please make reference to Chapter 13 of this report for the recommended structures to support suggestions herein.

4.1 Current Status

Currently, practice regarding the identification, referral and initial assessment of children on or suspected of being on the autistic spectrum, varies throughout the country. Health Boards have responsibility for the provision of an assessment and diagnostic service in respect of persons with an ASD. The structure through which this is done can vary. In one Health Board it may be carried out by Regional Diagnostic and Assessment Services for ASDs, in another by Mental Handicap Services, in another by Child and Adolescent Psychiatric Services, in another by voluntary service providers and in yet another by disability or child and family services.

Ready to Learn (1999, section 2.2) states that the Partnership 2000 Expert Working Group lists eleven Departments as involved in the child care area. This obviously leads to overlaps and oversights, and highlights the need for coordination and integration of services:

...lack of coordination has been identified by the National Forum for Early Childhood Education, among others, as a significant problem inhibiting the development of adequate systems of early education and childcare. [Ready to Learn (1999), section 2.4]

A meeting of over 50 parents, providers, organisations and professionals in the field of ASD from Dublin, Kildare and Wicklow Counties (June 2000) identified co-ordination between the Department of Health and Children and the Department of Education and Science as their number one priority. The lack thereof is contributing to the slow development of services generally.

Submissions received, primarily but not exclusively from parents, reflected not only the difficulty in securing a diagnosis, but the immense frustration that can accompany the process.

4.1.1

A number of disciplines, as well as parents, are ideally involved in providing a comprehensive assessment of the child suspected of being on the autistic spectrum. In the vast majority of cases, those better acquainted with the disorder can confidently diagnose children who meet the criteria for specific ASDs at a very early age. The child with more classic forms of autism may be diagnosed as having a Specific Speech and Language Disorder or a General Learning Disability, (mental handicap) or may not be provided with a diagnosis for a protracted period of time. The identification of children and young persons with AS / HFA is particularly problematic, and identification rates for this group are extremely low when compared to internationally accepted prevalence rates.

An early diagnosis helps parents to understand why their child's behaviour is so unusual, enables them to focus on learning about and meeting their child's needs, and allows them the time necessary to secure appropriate services and schooling. Autistic spectrum disorders are very serious, but are amenable to intervention. Early detection is of critical importance as early intervention can reduce some of the symptoms, and improve the outcome (Lovaas, 1987; Mesibov, 1997; Sheinkopf and Siegel, 1998; Sines 1996).

The experience of many parents in Ireland to date, has been to have received reassurances from health professionals that their pre-school aged child is fine, only to find later that their fears were very well founded indeed. Parents may be further blocked in their efforts to secure a clear diagnosis where they are restricted to access only a particular service provider in a geographical area, and are deemed ineligible to access a second opinion from within the public or voluntary health or mental health sector. Those with the resources may then revert to securing a private evaluation or consultation with a known expert, for example Psychiatrist, Psychologist or Speech and Language Therapist, or go to an ASD specific clinic in England. The Task Force is concerned that in some circumstances primary providers have then refused to continue to work with the child and family as a result. This reflects the now acknowledged rigid boundaries around service provision that are unhelpful to a family in distress.

In other cases, professionals have diagnosed children as having 'autistic-like' behaviours. In the vast majority of cases, those better acquainted with the disorders can confidently diagnose children who meet the criteria for ASD at a very early age. Children with an ASD may receive a diagnosis of Expressive-Receptive/ Semantic-Pragmatic Language Disorder from a Speech and Language Therapist. This may be accurate, but identifies only part of the clinical picture. Speech and Language Therapists are often the first to recognise an ASD, but are not professionally in a position to diagnose. Some children may further be

identified as having a global developmental delay (general learning disability). This too may be true, but once again does not account for all of the symptoms presented. So, parents are faced with the frustrating situation where each professional they meet gives them a different diagnosis, each plausible, but not fully explanatory of their child's condition. Why does this happen? It happens because professionals not routinely familiar with the disorder, will understandably remain within the areas associated with their own profession, and will utilise assessment tools specific to their area of expertise. Additionally, many characteristics common to ASDs may also be present to some degree in children with other difficulties, e.g. Language Disorder, Attention Deficit Hyperactivity Disorder, and Intellectual Disability. To further complicate matters, ASDs present a wide spectrum of symptomatology and so can look very different from one child to the next. Given that ASDs are characterised by a Triad of Impairments, all of which occur simultaneously and at varying degrees across children, it typically requires a multi-disciplinary assessment to establish a definitive diagnosis. This approach has not been available in most areas of Ireland, and, where it has been, the personnel involved may not have yet been fully informed about ASDs.

4.1.2

The difficulty arising from fragmented assessment is mentioned in a submission comment from the parents of a nine-year old boy:

At the moment the assessment procedure is piecemeal, with different professionals making separate reports and filing separate lists of recommendations.

A diagnosis of an ASD has the potential to impact negatively on the functioning of entire families where appropriate support is not available following diagnosis. Early diagnosis is central to the identification of effective home based and pre-school programmes and gives families an opportunity to accept and come to terms with the implications of diagnosis before additional difficulties occur.

A submission from a parent association representing approximately 400 people with AS/HFA also reiterates the need for improved identification of this group:

Very often vital formative years had passed without diagnosis due to lack of resources or downright failure by the existing structures to recognise and diagnose the problem.

There were some striking cases in which family members wrote of the immense difficulties they had in acquiring a diagnosis of Asperger's Syndrome. The trauma which was involved is illustrated in the extracts that follow.

...It has taken me fourteen years to get a diagnosis (for my daughter) during which time my family and I have endured the most terrible ordeal. The torture is still ongoing... Getting a diagnosis was essential and took constant fighting for answers from professionals for many years. Consulting professional after professional who did not and would not fully identify my daughter's problems. Looking back, from an early age she presented with many traits of autism....

Similarly, a sister of a man with AS wrote:

... was 22 years of age when he was diagnosed. After many years of testing, assessing and analysing with no definite outcome or diagnosis, we have finally found a reason for --- being a 'little different'.... Both --- and I have found answers to many questions that had bothered us for 22 years. In one way, it has been a great relief to find that he is not alone in this world...

Many submissions to the Task Force refer to the fragmented nature of current assessment and diagnostic procedures and services, whereby assessments may result in late diagnosis, misdiagnosis or, at times, no diagnosis at all. The Task Force is aware of many young persons with AS/HFA who were not diagnosed until they were sixteen or seventeen years old, despite years of contact with professionals. Such delays mean that a substantial number remain unidentified and unsupported, perceived perhaps as odd loners, with the true extent of their difficulties often undetected and unacknowledged outside the home. The problems encountered by parents who are routinely referred from one service to another over the course of years, in search of diagnosis for their child's 'difference' are unnecessary and unacceptable. There is currently no comprehensive identification system operational and there is no AS/HFA database or specific designated service provider.

4.2

4.2.1

Low awareness of AS/HFA among health and education professionals and insufficient understanding of the characteristics and impairments associated with AS / HFA has led to severe difficulties for families who may be excluded from intervention and support services or offered inappropriate advice and treatment for misdiagnosed conditions. This has also led to undue delays in securing adequate support services and has resulted in a situation where the educational, health, therapeutic and social requirements of a substantial proportion of this group continue to be unrecognised and remain unidentified by state agencies throughout their school lives. Often, by the time an accurate diagnosis is reached, there are significant additional difficulties to be unravelled and valuable early

intervention opportunities have been lost. Late diagnosis of AS / HFA precludes the majority of pre-school children and many primary/secondary age children and their families from availing of the benefits of early intervention and appropriate educational, clinical and family support.

Many of those diagnosed during late adolescence have already outgrown designated health and education provision and are forced to rely entirely on their families for support. Lack of clear 'ownership' and a designated service provider to meet the needs of those with AS / HFA adds to the confusion. (SWAHB, 2001). Families are isolated, carrying an enormous burden of care and under immense stress. Detailed analysis of differential diagnosis of Asperger Syndrome (Fitzgerald, 2000), reveals the complexity of issues currently surrounding diagnosis (see Chapter 2). The complexity and importance of differentiating between Asperger syndrome and other conditions, and the importance of early diagnosis are repeatedly highlighted throughout the Report of the Working Group on Asperger's syndrome (SWAHB, 2001), which recommends that:

The appropriate professionals should come together to agree a common diagnostic formula for AS / HFA for the purpose of diagnosing the condition as early as possible.

The Working Group recommend that an information campaign be mounted to inform the primary and secondary levels of the service about the importance of the early detection of children with AS / HFA. Each child should have a comprehensive treatment plan formulated and delivered to them.

The need for greater understanding and more knowledge regarding the whole area of AS / HFA has been noted by the Working Group and it has been suggested that consideration be given to hosting a conference of seminar, national or international, to bring together the best thinking on this subject. New ideas and innovative ways of tackling the difficulties confronting both individuals with AS / HFA and their carers should be shared with a view to improving the service. (pp.39-43)

4.2.2

The Task Force endorses the views and above recommendations of the Report on Asperger's Syndrome in this regard and recommends:

- a) that assessment and diagnostic services be provided across the age span, to accommodate diagnosis of those who have not, and will not be picked up at the early identification stage, and
- b) that the Departments of Education and Health should co-ordinate a National Asperger's Syndrome / High Functioning Autism Awareness Campaign

aimed at teachers, parents and the medical profession in an effort to combat current low levels of awareness and in doing so, improve identification rates for persons with AS / HFA, and

- c) that a working group which would include representatives the Department of Health and Children, the Department of Education and Science, Parent representatives, social services and other relevant parties, be established in each health board region, the co-ordinators of whom would meet at National level to identify and review the specific needs of people with AS / HFA throughout the life span.

4.3

Following diagnosis, the goal of further assessments is to identify how the disability affects the individual in his or her day-to-day life and to plan appropriate assistive intervention. This secondary function of assessment provides a baseline from which a student's progress and needs can be monitored as s/he moves through the educational system. This is particularly relevant to children with ASDs as their profile of strengths, weaknesses, behaviour and needs may change, sometimes dramatically, during the preschool and primary school years. An ongoing schedule of assessment is required on multiple levels, e.g. teacher monitoring of individual skills, annual goals and short term objectives and related methodology on a daily or near daily basis; informal assessment and formal testing in each of the clinical areas; emotional status of child and family; family needs; related medical needs; assessment to develop and revise 'life plans'; and behavioural assessment to facilitate improved learning and social skills. To date, Ireland has been lacking in all of these areas. In a recent Irish study (Murray, 2000), 52% of parents of a child with an ASD reported that there had been either none or only rare reviews since their child was first diagnosed. Many parents of children with AS / HFA report that they have never had their children's needs reviewed.

4.4 Screening & Referral

Studies indicate that approximately 25% of all children present with developmental issues but that fewer than 30% of primary care practitioners conduct standardised screening tests at well child appointments. The Murray ERHA (2000) study found that 87% of parents of children with ASDs expressed concerns about developmental delays at a very early stage. 77% reported this to their GP's and 28% of them were assured there was no problem. The 12-24 month Public Health Nurse check-up, identified concerns in 33% of the cases. By the time that their children had reached four years of age, 56% of the parents still had not been provided with a clear diagnosis.

Failure to meet conventional developmental milestones should result in a referral for further evaluation. Parents should be recognized as equal partners in the

process, and whenever parents inform health or education professionals that they believe that their child may have an ASD, the child should immediately be referred for diagnostic assessment as studies reflect a 75-83% rate of accuracy in parents identifying a disability in their child. Twenty-one submissions from parents confirm that parents are becoming increasingly well versed in both the formal diagnostic indicators, and the practical problems that result. Parents of children with ASDs are often the first to notice that their child is 'different'. The difficulties encountered by parents who are referred from one service to another, over the course of years in some instances, in search of a diagnosis for this 'difference' are unimaginable. Often, parents report that the current systems of referral, assessment, diagnosis and support / intervention are as problematic and stressful to cope with as the condition itself.

A national and wide-ranging awareness initiative aimed at the general public and at Health / Education personnel through the Department of Health and Children should be conducted. As the Primary Health Care Professional, the General Practitioner or Paediatrician is typically the first person who will suspect or be informed of developmental concerns. This initiative would ensure that Primary Care Providers become familiar with early diagnostic screening tools for ASD, and the nature and prevalence rate of ASDs. Once alerted, they should *immediately* initiate a complete medical screening, and simultaneously refer the child to the Secondary level of health care, i.e. their local Health Board Child and Family Centre. To further facilitate early identification, it is recommended that all Public Health Nurses in the Republic incorporate a screening tool for ASDs into their 18-24 month checks. Currently, the Checklist for Autism in Toddlers (CHAT) or equivalent could meet this need. It must be highlighted, however, that to date, such tools are of little use in identifying very young children on the high end of the spectrum. The importance of early diagnosis and the likelihood of continuing need for adolescent/adult diagnosis of persons with AS/HFA who have been missed in the past, should be highlighted among primary and secondary levels of the health service.

One submission to the Task Force stated:

It is imperative that all public health nurses, GPs and child specialists be brought to seminars to diagnose the autistic problem very early in the child's life. Every month is vital...

This highlights the need for information on diagnostic indicators of AS / HFA and Autistic Disorder to be disseminated to primary health care professionals.

Speech and language therapists are often the first clinicians to be involved with children who are subsequently diagnosed as having an ASD. Training courses for Speech and Language Therapists, therefore, must include a module on the differential diagnosis of ASDs, specifically including Asperger's Syndrome as well as Classic Autism, both of which may present to Speech and Language

Therapists as Semantic Pragmatic Language Disorder. Until this is in effect, a system of inservice for all Speech and Language Therapists within the Health and Disabilities Services must be established. At the point at which they suspect a child may have an ASD, Speech and Language Therapists should refer the child for a more comprehensive diagnostic assessment.

The child may be referred to a specialist ASD Diagnostic & Assessment service, the Child and Family Centre, or the local designated Service Provider. Due to waiting lists for clinical and specialist educational service provision, the service which will result in the most immediate attention should be pursued. Excluding truly exceptional circumstances, the wishes of the parents for referral to a particular service provider should be honoured.

Children with Asperger's Syndrome are typically not diagnosed until after primary school entry, and there is evidence that many children are never detected at all. The National Educational Psychological Service is committed to addressing these concerns and over 40 NEPS Psychologists recently attended a training workshop on the identification and educational support of students with AS/HFA. These psychologists, with parental collaboration, can conduct preliminary screening and refer as appropriate to the regional Health Board's ASD team/diagnostic service for a full multidisciplinary diagnostic assessment. NEPS is also preparing information packs for newly appointed psychologists and for primary and secondary schools and parents around the issues of identification of children with Asperger's Syndrome, and the promotion of sensitivity to their needs at the school level. Thus, there are various routes to the receipt of a diagnosis and while existing practices are at times good and sufficient, the Task Force supports the view that regional diagnostic clinics should be established to provide third-level diagnostic teams.

4.5 Diagnostic Assessment

4.5.1

The purpose of the assessment is to gather information as a basis for diagnosis and intervention. Assessment should lead to:

- i) an accurate diagnosis
- ii) meaningful conclusions from which an appropriate intervention plan in respect of the individual child and family can be developed

Additional purposes of assessment include establishing baseline information on which future comparisons can be made, identifying possible concomitant difficulties e.g. sensory dysfunction and language deficits, identifying areas of strength, contributing towards understanding of the prognosis, and directing the

child's team, which includes the parents, towards relevant goals and objectives and the instructional methodologies which might be best suited to the child.

4.5.2

Teachers in existing classes for children with ASDs in Ireland (Kinsella, 2000) have also identified the assessment of the level of intellectual functioning as highly significant to their teaching. They have found that knowing whether the ASD or, in some cases, the existence of an additional cognitive disability is the primary barrier to learning, would be highly relevant in configuring the class, the curriculum to be followed, and teaching procedures utilised. The Task Force acknowledges the need to identify intellectual levels of functioning and primary barriers to learning. Some differentiated models of provision for children with an ASD will need to be established to ensure that this need is reflected in practice and models of provision.

Professionals are reminded that certain assessment tools are developed for use by specific disciplines and should be used only by those who are appropriately qualified to do so.

Another critical consideration, is the way in which results are shared with parents. Extreme sensitivity needs to be effected when imparting the definitive diagnosis to parents. The manner in which parents are informed remains with them throughout their lives.

Submissions to the Task Force reflect the impact that receiving the diagnosis in an unsupportive manner has on the parents. Two excerpts are provided here as examples:

i) Our daughter was diagnosed by a paediatrician over two years ago. At that time, the doctor in question gave his diagnosis in a very negative manner. We were told at that time that there was nothing that could be done for our child and that her condition would probably deteriorate.

ii) We were not given any counselling on this condition or any contact numbers for any assistance, It was a devastating reality we had to face up to and accept, but wouldn't it have been comforting for the doctor at that time to have given additional advice and perhaps a list of contacts to get in touch with for advice. We honestly think that the members of the medical profession who are going to diagnose these conditions should have some sense of compassion and understanding, and maybe some further training in dealing with these circumstances along with all the relevant information required.

The examples described above show a marked lack of empathy and understanding, and may reflect a lack of knowledge about the condition itself. If a diagnostician is not sufficiently familiar with ASDs, he/she should refer the child and parents for a definitive diagnosis to the ASD regional diagnostic services or to another diagnostician with more experience in ASDs. Diagnosis of ASDs should be restricted to psychiatrists and psychologists who have appropriate training and have developed a specialism in the area of ASDs. Parents should also be provided, in writing, with a description of the appeals procedure (see Chapters 13 and 14) early in the assessment process.

4.5.3

As no biological markers of ASDs have been identified, symptoms sets from a range of specified behaviours are used in the diagnosis of an ASD. A number of checklist-type instruments are used by professionals to facilitate the application of DSM and ICD-10 diagnostic criteria. The importance of clinical judgement should never be underestimated. For example, Howlin (2000) notes that it is unrealistic to assume that any one instrument can be used in isolation to ascertain diagnosis of AS / HFA. Detailed information on cognitive, linguistic levels, family history, medical, social, psychiatric and if possible, genetic background will also be required in order to differentiate ASDs from seemingly similar conditions (Rutter et al., 1999; Volkmar et al., 1999; Filipek et al., 1999).

The more frequently utilised assessment tools include:

- *Screening Questionnaire for Asperger Syndrome and other high functioning autism disorders in school age children (ASSQ)* (Ehlers, Gillberg, & Wing, 1999) This is a 27-item checklist for completion by lay informants. The items covered are derived from the clinical criteria of Gillberg & Gillberg (1989) and are rated on a 3-point scale. This is the only screening instrument specifically for AS / HFA for which detailed reliability and validity data are available.
- *Asperger Syndrome (and high-functioning autism) Diagnostic Interview (ASDI)* (2001), a 20 item rating scale based on a highly structured interview by a clinician with a first degree relative of adolescents and young adults. This is a longer diagnostic interview based on the ASSQ. Initial findings suggest that this instrument has acceptable levels of reliability and validity (Gillberg *et al.*, in press).
- *Australian Scale for Asperger Syndrome*, a 34 item questionnaire completed either during a clinical interview or by the parents, or a teacher who knows the student very well. It can be used as a screening instrument for older students and high functioning primary aged children, to determine the need for a full diagnostic assessment.
- *Autism Diagnostic Interview - Revised (ADI-R)* (1994), a semi-structured interview for use with caregivers of young children who are presenting with behaviours suggestive of autism.

- *Autism Diagnostic Observation Schedule- Generic (ADOS-G)*, which consists of a standard protocol for observation of social and communicative behaviour associated with autism. The ADOS-G includes four modules, defined in terms of the child's expressive language capacity. It complements information obtained with the ADI-R, which is informant based.
- *Checklist for Autism in Toddlers (CHAT)*, not for use as a diagnostic instrument, it is used in screening to identify core autistic features to enable treatment to begin as early as eighteen months
- *Childhood Autism Rating Scale (CARS)*, a 15 item behaviour rating scale for use in respect of children older than two years of age who are presenting with behaviours suggestive of autism. Having observed the child, and taking account of information from caregivers, teachers and others, the examiner rates the child on a seven-point scale on each item. A child with a score above a certain point is regarded as *autistic*, either *mild-to-moderate* or *severe*.
- *The Diagnostic Interview for Social and Communication Disorders (DISCO)*, a semi-structured interview, developed and utilised at Elliot House, UK as both a research and clinical tool. (Note that to access this tool, one must undergo a full week of training with authorised trainers.)
- *Gilliam Autism Rating Scale (GARS)*, based on DSM-IV, can be used from age 3 - 22 years in diagnosing and in estimating the severity of autism.
- *Pre-linguistic Autism Diagnostic Observation Schedule (PL-ADOS)*, a semi-structured observation scale completed collaboratively with parents, for children who are not yet using two-word utterances and who are presenting with behaviours suggestive of autism.
- *Wing Autistic Disorder Interview Checklist (WADIC)*, Lorna Wing, 1996, a 22 category, 89 item checklist for use with all ages. A lengthy interview is conducted with the parents and others as needed, to complete the 5 page form.

It is important to note that many of the above diagnostic instruments may have been developed before the current DSM-IV-TR (2000) became available and may not yet fully reflect current diagnostic criteria. It is important to note also that most autism-related diagnostic instruments have been designed for use within a specific range of that population and may not be helpful or valid if used with a different portion of the population. Although the Autism Diagnostic Interview – Revised (ADI-R, Lord et al., 1994) and the Autism Diagnostic Observation Schedule-Generic (ADOS-G); (Lord, Rutter, & DiLavore 1996) can be helpful in diagnosing AS/HFA, there is little evidence that widely used instruments such as the Childhood Autism Rating Scale (CARS) and the Autism Behaviour Checklist (ABC) can be of assistance in the diagnosis of AS/HFA, as these instruments focus on a degree of symptom severity that is not generally found in this population (Klin et al, 2000).

The Task Force supports the recommendation of the Working Group on Asperger's Syndrome (SWAHB, 2001) that:

The appropriate professionals should come together to agree a common diagnostic formula for AS / HFA for the purpose of diagnosing the condition as early as possible.

4.5.4

The Task Force recommends the Health Board Regional Diagnostic and Assessment ASD specific diagnostic team model. It is important to highlight that diagnostic assessments should not be limited to ASDs, but address all possible difficulties and conditions, including, e.g. ADHD and mental health issues, so that any additional disorders may also be addressed. In areas where ASD teams do not yet exist or are unable to meet the demands of both assessment and service provision, a diagnosis of an ASD by a psychiatrist or by a psychologist who has a specialism in this area should be sufficient as a basis for access to an educational service. The child should subsequently be seen by the ASD team for collateral assessments and recommendations. This approach is not ideal, but in some situations may be more feasible.

4.6 Multi-disciplinary Assessment

4.6.1 Pre-school Identification, Referral and Assessment

Health Board Child and Family Centres (or other services operating under the aegis of Child Psychiatry) or Designated Health Board Regional ASD Services are currently charged with providing the multidisciplinary diagnostic assessment for any child suspected of having an Autistic Spectrum Disorder. ASD intervention Co-ordinators are already in place in some Health Boards although core intervention teams are urgently needed. Their function is to coordinate the provision of Intervention Services. The Task Force endorses the establishment of these ASD Services, and recommends that all Health Boards proceed to establish them fully as a matter of urgency.

In some cases, definitive diagnosis of the Autistic Spectrum Disorder can be offered prior to every member of the multidisciplinary team completing their full evaluations. In an ideal world, all assessments would be completed within a brief period of time and the formal designation of the disorder would follow. Realistically, however, full multidisciplinary teams are not yet available. In this situation, relevant professionals should be employed on a sessional basis by Health Boards to form the independent regional assessment and intervention teams so as not delay the delivery of needed educational and clinical services. It is essential that the assessment and service provision functions should be independent of each other and that the assessment process is transparently free of any vested interest.

For some children, their presentation makes it very difficult to make a definitive diagnosis prior to an extended period of observation during which on-going assessment is conducted. During the assessment period these children should be eligible for any specialised educational programmes and clinical services available to children with ASDs. In any case, if nine months lapse and the child is not yet in receipt of a definitive diagnosis, the Task Force recommends that such children be referred to an alternative service provider for an independent second opinion.

4.6.2 Referral for Special Educational Support

Following the diagnosis, the child or young person should be referred to the Health Board ASD Intervention Services Co-ordinator or corresponding official, who should then alert the regional Special Needs Organiser (recommended in the Department of Education and Science *Report of the Planning Group: A National Support Service for Special Education for Students with Disabilities*, 2000, and also envisaged in the structures to be established by the recently announced National Council for Special Education – see Chapter 13). If someone other than the Regional Diagnostic Services makes the diagnosis, the child should then be immediately referred to the ASD Intervention Service. **In the interim**, relevant professionals should be employed on a sessional basis by Health Boards to form the independent regional assessment and intervention teams so as not delay the delivery of needed educational and clinical services.

Following a diagnosis, the ASD Intervention Services Co-ordinator will, in liaison with the parents, arrange for the immediate preparation of a provisional Child and Family Support Plan. Simultaneously, s/he will inform the Department of Education and Science in the person of the Special Needs Organisers (pending their establishment the Department of Education and Science Inspectorate). The Special Needs Organisers, in conjunction with the parents and members of the Intervention Services, would identify and record the child's global educational needs, and organise any specialised educational provision thereby designated.

4.6.3

A multi-disciplinary team consisting of designated Department of Education and Science and Department of Health and Children staff agreed for each child, will then be required for the full formal statutory assessment of educational needs of children with ASDs, i.e. following diagnosis. The Task Force recommends that a Department of Education and Science Autistic Spectrum Disorders Educational Planning and Advisory Service operating under the new structures be established in each region. It is envisaged that the drawing up and implementation of the educational plan would be the responsibility of this Service, in conjunction with the child's designated teacher(s) and parents. The assessment process should be carried out in a collaborative way with parents and other relevant professionals and agencies. Responsibility for each component must be clearly specified. The

medical, social services, and more specialised assessments would typically be the responsibility of Health, while the educational, learning, and practical skills assessments would be primarily the responsibility of Education. It is envisaged that the Health Board clinical psychologist would play a key role in the process of drawing up the statutory assessment of educational needs as well as the Individual Education Plan. The NEPS psychologist would also assume increasing responsibility in this area as staffing resources permit and will of course be involved in the subsequent monitoring of the child's progress following school placement. (This will require the expansion of NEPS well beyond the numbers included in their current Development Plan). This formal process should not delay the more immediate enrolment of a child with an ASD be in an appropriate educational placement which would be based on the least restrictive environment, and considered as an ongoing course of action which, depending on the individual child's presentation and parental wishes, may include:

- an examination and evaluation of the child's sensory status (hearing, vision, including e.g. visual skills such as tracking, depth perception and auditory skills such as source-sound matching, auditory discrimination, etc.
- interviews with parents, teacher and , where feasible, the child
- direct behavioural observation in multiple settings
- completion of checklists by or with parents or caregivers
- formal psychometric evaluation of the child's cognitive, social, emotional, behavioural and adaptive functioning
- an evaluation of literacy and numeracy readiness or attainment
- an evaluation of skills involved in the activities of daily living
- a functional analysis of targeted behaviours (in cases where behavioural difficulties have been identified)
- an evaluation of learning style (e.g. preference for verbal or visual instruction; how child best scans and focuses to receive visual information); how to best gain the child's attention) and problem solving approaches
- an examination and evaluation of the child's gross and fine motor skills, of sensory integrative functioning, and lateral dominance
- an evaluation of mental health status and possible affective disorder
- an assessment of the child's social status with peers.

It falls to each professional discipline to keep an up to date knowledge base on the best assessment tools and strategies for conducting assessments, and any ongoing or periodic re-assessments that are indicated. The following suggestions regarding assessment domains may constitute a useful guide. The domains in a comprehensive assessment should consider the student's chronological age and general level of functioning, and may include, but are not limited to, the following:

- Cognition/developmental levels
- Social/emotional skills
- Sensory regulation

- Motor skills
- Communication skills
- Play/leisure time activities
- Pre-academic/academic skills
- Prevocational/vocational skills
- Self-help, independent living skills
- Community based skills
- Behaviour
- Relevant medical assessments such as connective tissue disorder, mitral valve dysfunction, thyroid disease, visual impairment, ligamentous laxity, maldescended testicle or dietary intolerances
- Genetic screening for Fragile X should automatically follow diagnosis of an ASD.

4.6.4

The outcome of assessments should be the production of a holistic profile of the child, which leads the parents and all involved to the identification of needs and the development of a formal, statutory Health Board Child and Family Support Plan, a statutory Statement of Educational Needs and an Individual Education Plan. Statutory entitlement to a Child and Family Support Plan, a Statement of Educational Needs and an Individual Education Plan should be established as soon as possible. Further references to the Child and Family Support Plan throughout this report refer also to the Adult and Family Support Plan although this is not explicitly stated in every instance. Parents should be fully informed of all entitlements and all those diagnosed with an ASD should be provided with a medical card. Assessment would also be the basis for the goals and instructional methodologies most suited to the child.

4.6.5

After a diagnosis of an autistic spectrum disorder has been made or appears probable it will be necessary to gather more specific data regarding individual competence in discreet areas of development as a basis for the full identification of special educational needs. There are a large number of inventory-type instruments that can be used by clinicians and teachers in this process. Examples of Autism specific tools are:

- *Autism Screening Instrument for Educational Planning (ASIEP-2)* - used from age eighteen months onwards. It provides a standardised framework for collecting data across five areas, *sensory, relating, body concept, language and social self-help*, as a basis for educational planning.
- *Psychoeducational Profile-Revised (PEP-R)* is a skill and behaviour inventory for children with autism or similar developmental disorders who are functioning at pre-school level and in the age range six months to seven years. It can be used to provide information regarding functioning in

imitation, perception, fine and gross motor, eye-hand integration, cognitive performance and cognitive verbal areas. It can also be used to identify degrees of behavioural abnormality in relating and affect, play and interest in materials, sensory responses and language. It was designed to be administered by educational personnel.

- The *A-PEP* is the Adolescent version of the PEP and geared towards those with an intellectual disability as a co-existing barrier to their learning. Each of these can be teacher/clinician made from the materials lists in the *A-PEP* Manual.
- *Pre-verbal Communication Schedule* (Keirnan & Reid, 1977), was designed for those exhibiting very low or no intentional communication and has been validated on children with autism. It is useful in helping teachers and others recognise the communicative potential of even destructive behaviour.
- *Real Life Rating Scale (RLRS)* is used to assess progress across 47 behaviours in motor, social, affective, language and sensory functioning in children with autism.
- *Vineland Adaptive Behaviour Scales, Interview Edition* is completed with parents as the informants and provides relatively comprehensive information on skills in the following domains: communication, socialisation, daily living, motor, and maladaptive behaviour. There is also a *Teacher's Edition* available.

A further list of instruments is provided in the California Departments of Education and Developmental Services sponsored *Best Practices for Designing and Delivering Effective Programs for Individuals with Autistic Spectrum Disorders* (Collaborative Work Group on Autistic Spectrum Disorders, 1997).

Norm-referenced academic and process tests and other generally available assessment instruments are often appropriate for students with an ASD. The Task Force is of the opinion that, as a general practice, the identification of individual learning styles and special educational needs in respect of children with ASDs should be the joint responsibility of the parents and all individuals involved in assessing, teaching and providing clinical and educational support services. Where appropriate, the student him/herself should also be actively included in this process.

4.6.6

A provisional Individual Educational Plan should be written within 30 days of diagnosis and should include interim educational goals, methods and locations of delivery. As the teacher may not be familiar with the child, this will facilitate the early provision of suitable educational intervention.

*Screening by PHN and/or GP (or NEPS) →
Referral to local Child & Family Centre (and/or) →
Referral to independent HB ASD Diagnostic Team →
Definitive or Provisional Diagnosis →
Provisional Child and Family Support Plan (HB)*

and simultaneous
Referral to HB ASD Intervention Team Co-ordinator and
Referral to SNO for Provisional Identification of Special Educational Needs (DES)→
Referral to Educational Programme/School →
Provisional Individual Educational Plan within 30 days of diagnosis (DES & HB→
Initiate Interventions (HB & DES) →
3-6 months maximum for child to accommodate to new setting, if required
all to work with and further assess the child as needed →
Statutory Statement of Educational Needs (DES)→
Formal Individual Educational Plan (DES),
and
Statutory Child and Family Support Plan (HB)

It is essential that key members of the Health Board team, typically the Psychologist, Speech and Language Therapist and Occupational Therapist should attend the IEP meetings, as well as the teachers and parents concerned. It should be remembered that special educational needs do not just evolve from difficulties identified during formal assessments. They are also derived from the interaction of a child's strengths and weaknesses with particular environments. The more 'ASD-friendly' the environment and the greater the child's abilities, the less the child's identified difficulties will constitute special needs.

Following diagnosis, parents should have access to accurate information regarding mainstream and specialised educational options for their child. Information on a variety of empirically validated methodologies should also be available and the relative value of different options should be explored from the professional and parental perspectives before making decisions on educational placement. The need to make information easily accessible to parents was raised over and over again in multiple Task Force Submissions.

Thus, a comprehensive assessment will require a period of time to complete. This should not interfere with more immediate provision of services. As suggested in the flow chart above, a temporary, global Intervention Plan can be put into effect as soon as the child is suspected as being on the Autistic Spectrum. Other needed assessments will be part of this Plan, which can be revised once all relevant areas have been assessed. Then, in conjunction with the parents, this team writes the Child and Family Support Plan, which would become mandatory/statutory for Health and serve as the basis for preparing the formal Individualised Educational Plan (IEP).

The development of a Statutory Child and Family Support Plan is considered by the Task Force to be necessary to clarify and provide entitlements to therapies and supports which would be provided. This would be a multidisciplinary assessment of the unique strengths and needs of the infant, toddler, child or adult and the identification of services appropriate to meet such needs. It would include a family-directed assessment of the resources, priorities, and concerns of the family and the identification of the supports and services necessary to enhance the

family's capacity to meet the developmental needs of the person with an ASD. It would require a written individualized family support plan developed by a multidisciplinary team, including the parents (see: *Individuals with Disabilities Education Act Amendments of 1997*, Part C, Section 636. <http://www.ideapractices.org/lawandregs.htm>).

A provisional IEP should be prepared within 30 days of the Initial Support Plan. As with the Child and Family Plan, the Statutory Statement of Educational Needs and formal IEP would be constructed at a date agreed by the ASD Educational Planning and Advisory Service, the teacher(s), parents and support team, allowing up to 3 - 6 months (maximum) for the teacher to assess the student, for the clinicians to get to know the student in a more practical sense and, in some cases, for the student to adjust to his/her new environment.

4.7 Identification in the Primary Schools

Some children with ASD will not be diagnosed prior to enrolment in a National School. Typically such children are on the high end of the spectrum, particularly those with Asperger's Syndrome, as their condition is not always clearly obvious to adults/uninitiated clinicians/teachers, although peers appear to have no difficulty whatsoever in identifying (and often rejecting) 'differences' exhibited by those with AS / HFA even at the early stage. As the educational and emotional consequences of not being formally identified are significant, a system needs to be established to screen for autistic spectrum disorders. It is the view of the Task Force that every school should have a designated special needs co-ordinator, who will be a member of the teaching staff (as recommended in the 1993 SERC Report and already put into effect in some but not all schools to date). The designated special needs coordinator within each school should coordinate procedures for a baseline developmental assessment on each child, for comparative evaluation and identification for special needs purposes. Standardised screening tools should be specified and distributed by the Department of Education and Science, in conjunction with the National Educational Psychological Service, with guidelines for follow-up.

When a teacher or parent has concerns about any child at any point during primary school, the school should have a procedure, with the permission of the parents, to refer the child for evaluation, e.g., to the NEPS Educational Psychologist for preliminary screening. Where necessary, the child can then be referred to the local Department of Health Child and Family Centre, and/or the ASD Regional Diagnostic and Assessment Service for further evaluation. In fact, such procedures should already be in place as the 1998 Education Act specifies that:

All schools should have a clear written policy and procedure in regard to the identification and assessment of pupils with special needs, including those with disabilities.

The referral should then be followed by the multi-disciplinary assessment and statutory procedures, outlined above in section 4.6.6.

4.8 Identification at Secondary Level

4.8.1

Routine under-diagnosis and late diagnosis of AS/HFA indicate that identification is not just an early childhood issue. Relevant professionals should be provided with training opportunities to develop expertise in the area of AS / HFA and to assist recognition that persons with AS/HFA have distinct needs from those with autism with learning difficulties. Education and intervention for those with AS/HFA should not be equated with that available to those with ASDs and additional intellectual disabilities as age and ability-appropriate provision is critical to the emotional well being of many of this group. There are additional and hidden stresses on families where diagnosis is not made until adolescence, as decisions regarding appropriate intervention are reliant on the co-operation of the individual who may already have developed secondary difficulties and may have endured untold experiences of social exclusion, peer rejection, anxiety, isolation, loneliness and feelings of failure as a result of communication and social impairments. The Report of the Working Group on Asperger Syndrome (SWAHB, 2001) and the results of a survey carried out by ASPIRE as part of the same report captures the plight of this group well:

While a strong emphasis in this report is on the early and primary school needs of children with AS / HFA the plight of those children at secondary school level and beyond is even more problematic. (p.22)

The survey also showed the crucial need for educational and home support particularly when the child with AS/ HFA reaches secondary school, when many of these children drop –out of school. This puts enormous pressure on parents to try to redress the situation and continue the child's education. (p.29)

Persons identified with AS/HFA (or any other ASD) at second level should also be eligible for the assessment and educational and support procedures outlined earlier.

4.8.2 Information and Awareness of Professionals

Staff members with a pastoral responsibility such as school-based special needs co-ordinators, Guidance Counsellors, Year Heads, and co-ordinators of special programmes such as Youth Reach, require information packs regarding AS/HFA to enable them to be sensitive to the possibility of the presence of the condition when they are informed of students who are on the margin socially, are bullied, exhibit unusual behaviours, or who otherwise bring themselves to the attention of

staff. These information packs should be developed by the Health Boards' ASD teams and the National Educational Psychological Service in conjunction with the regional Special Needs Officers, when established, or the Inspectorate.

Where appropriate, and with parental agreement, these staff members should then notify their National Educational Psychological Service or Vocational Education Committee (V.E.C.) psychologist of their concerns. The relevant psychologist may then conduct preliminary screening and, where appropriate and following consultation and agreement with the parents and relevant colleagues, refer the child to the Regional Diagnostic and Assessment Service. Alternatively, the psychologist may decide to refer the child directly to this Service, without further investigation, where such referral appears warranted. As outlined in 7.9.1 below, the NEPS psychologist may choose to consult where necessary with the regional colleague with a specialism in autism. The Regional Diagnostic and Assessment Service will in turn liaise with the local Department of Education and Science ASD co-ordinator following an AS/HFA diagnosis. Persons identified with AS/HFA (or any other ASD) at second level should also be eligible for the assessment and educational and support procedures outlined earlier.

4.9 Identification at Third Level and Post Secondary Level

Third level Colleges and Institutes of Technology have Disability Officers. Most also have Student Counselling Services. Materials on the identification, needs and methods of support for students with AS/HFA should be routinely distributed to Disability Officers, Student Counselling Services and those in charge of Post Leaving Certificate programmes and they should be placed on the mailing list and invited to attend inservice training sessions supported by the Department of Education and Science and ASPIRE. For example, information and material for a short overview of ASD should be developed by the Department of Education and Science in conjunction with Health. Third level institutions and FÁS/CERT training centres could then arrange information sessions for new Disabilities Officers, or other staff with responsibilities for students with disabilities and, where applicable, for Student Counselling Services staff on an annual basis. These services should develop procedures, possibly through their own national professional organisations, to identify and offer appropriate support to those students in their college who have an ASD.

Formal presentations should also be made to Third Level and Post Leaving Certificate tutors who are often the first to be made aware that students in their Department are having difficulties. They should liaise with their Student Counselling Service when an ASD is suspected.

4.10 Assessment to Identify Special Educational Needs

4.10.1

As indicated earlier, diagnosis of an ASD should guarantee that a provisional multi-disciplinary Child and Family Support Plan and a temporary Individual Educational Plan is put in place within 30 days of diagnosis. The formal Individual Educational Plan and statutory plans are scheduled for an agreed date, but not later than 3 - 6 months following the provisional plans. Regular review and progress reporting should be incorporated into each.

Agreed protocols should be established between Health Boards and the National Educational Psychological Service to ensure uniformity and continuity between the assessment, diagnostic, review and support services of these two agencies. Protocols would include:

- requiring that all staff have appropriate training in ASDs;
- offering diagnostic and follow-up assessments to people of all ages;
- the provision of this service within a fixed time frame;
- use of up to date and accepted criteria for diagnosis;
- ensuring that regularly monitored quality assurance systems and performance standards, which include the feedback of service users, are in place;
- such systems and standards should be regularly monitored and evaluated based on numbers diagnosed annually, time scales for definite diagnosis, user satisfaction, and systems of referral;
- further assessment(s) and/or independent second opinions should be available where there are concerns regarding definitive diagnosis, the presence of additional disorders, or disagreement amongst the primary parties.

4.10.2

The issue of on-going assessment and review was raised in most of the 28 submissions dealing with the topics of identification and diagnosis. For the most part, yearly re-assessments were suggested, in addition to those required facilitating planning for transition to another stage in the educational process. Due to the nature of tests, good practice in the field of psychometrics requires that the same test instrument not be re-used more frequently than every 3-5 years in formal re-assessments. Individual Educational Plan reviews could be called for more often and the next date should be specified at each IEP meeting, though they are typically reviewed annually.

4.11 Collaboration by Psychologists

4.11.1

Educational, clinical, counselling and community psychologists have distinctive but complementary and, at times, overlapping roles in the provision of psychological support to children and their families. Inter-Agency co-operation

between the relevant health, voluntary and educational authorities is therefore of utmost importance. It is essential that formal links should be established between the National Educational Psychological Service and the relevant Health Boards at senior administrative level in each locality, and this process has in fact already been initiated. Such liaison is facilitated by the fact that the National Educational Psychological Service is organised in Regions corresponding to the 10 Health Board areas. It is envisioned that a National Educational Psychological Service colleague in each Region will have a specialism in the ASD area. This colleague would act as a general resource person to the National Educational Psychological Service psychologists working in each Region, and would also act as the main link person with the relevant Health Board and Non-Governmental Organisation services.

The Special Needs Organisers and the National Educational Psychological Service should be involved as soon as the child is ready to enter the pre-school/school system. In the case of any individual child, the Special Needs Organiser and the NEPS psychologist working in the area where the child resides are the appropriate colleagues to be consulted regarding pre-school/school placement, although primacy regarding decisions on placements ultimately rests with parents. The issues of NEPS involvement with pre-school children and the need for close collaboration between clinical and educational psychologists in relation to pre-school children with ASDs are further discussed in Chapter 7.

Following placement, the National Educational Psychological Service psychologist should have a major responsibility, in conjunction with the school staff, parents and other professionals involved, for the subsequent monitoring of the child's progress. S/he would also access the professional support of specialist colleagues as appropriate, and contribute to the multidisciplinary IEP process.

The Department of Education and Science inspector and Special Needs Organiser, and the National Educational Psychological Service psychologist, where appointed, will be able to provide information on the most appropriate Montessori, Community, Private or specialist preschool programme or primary/secondary placement based on their knowledge of the educational provision in the area. The Inspector will subsequently advise the receiving school on how to access the various support systems, including ICT resources, which were deemed appropriate at the specification of specialised educational needs meeting. This is in keeping with the SERC report (1993) recommendation stating:

Assessment reports should be sent to the Principal of the school recommended for the child. The Principal, or another nominated teacher, should be consulted by a member of the assessment team prior to the enrolment regarding the special provision which will need to be made, if the child's special needs are to be adequately met. (p.34)

The provision of reports to schools should be on a need to know basis. A major purpose of assessment is to provide an informed basis for intervention. Copies of all reports that are required to enable a school to reach a decision regarding the question of enrolment, to formulate an Individual Educational Plan or to assist the school in making the necessary accommodations for the child, and of those reports only, should be forwarded to schools. This is in respect of the confidential nature of collateral information on the child and family members, which educational purposes may not require.

The current target number of 200 NEPS psychologists to be employed by the end of 2003 will not be sufficient to realistically undertake the intensive individual work required for pupils with ASDs. Realistically, therefore, it may be some years before the National Educational Psychological Service is in a position to take a leading role within ASD educational provision. However, NEPS is about to undertake a mid-term review because of these and related considerations in the Special Education area, and it is hoped that an increase in staffing levels will eventuate, which will permit the educational psychologists to make their necessary contribution in relation to children with ASDs.

Until such time as the Special Needs Organisers and ASD teams are in place, assessment agencies should ensure that the relevant Inspector of Schools is provided with a copy of assessment reports sent to schools in support of referrals for special enrolment of children with an ASD. If the specialised programmes required are not yet in place, the child with an ASD should be temporarily supported in other local provision with the necessary level of support, and not left without formal educational intervention.

4.11.2 Assessment of Siblings

As genetic factors play a very significant role in the onset of autistic spectrum disorders, it is essential that a screening procedure should be developed for the siblings of diagnosed children, where this is in accordance with the wishes of parents. The majority of siblings will be fine, but others will also have symptoms of the disorder. Many siblings are less obviously affected, but still in need of support at the earliest possible time. If the siblings are younger than the diagnosed child is, a subsequent child on the spectrum might be identified early enough to significantly minimise the effects of the disorder. Sibling screening and assessment should be relegated to the Health Board ASD Diagnostic and Assessment Services.

4.12 Recommendations

The Task Force recommends:

1. that the Departments of Education and Health co-ordinate a National Asperger's Syndrome/High Functioning Autism Awareness Campaign aimed at teachers, parents and the medical profession in an effort to combat current low levels of awareness and identification rates; that

awareness be raised among professionals of the need for referral of suspected cases of AS/HFA to the appropriate secondary or tertiary services; that special training be provided within the relevant professions in relation to AS/HFA;

2. that a National ASD screening programme be established targeting Public Health Nurses and General Practitioners;
3. that Health Boards establish procedures for the assessment of possible ASD in the siblings of identified children;
4. that all Health Board and Department of Education and Science funded assessment and diagnostic services operate with uniformity; that they establish a defined template to follow; that this protocol include:
 - a requirement that all staff have appropriate training in ASDs;
 - diagnostic and follow-up assessments which are offered to people of all ages, where relevant;
 - the provision of this service within a fixed time frame;
 - use of up to date and accepted criteria for diagnosis;
 - the ensuring of regularly monitored quality assurance systems and performance standards, which include the feedback of service users;
 - systems and standards which are regularly monitored and evaluated, based on numbers diagnosed annually, time scales for definite diagnosis, user satisfaction, and systems of referral;
 - further assessment(s) and/or independent second opinions to be available where there are concerns regarding definitive diagnosis, the presence of additional disorders, or disagreement amongst the primary parties;
 - a comprehensive paediatric assessment, which includes the investigation of ASD-related conditions and symptoms, and is conducted as a matter of course;
5. that the Child/Adult and Family Support Plans, and Statement of Educational Needs be afforded statutory status; that an IEP be established for each individual, based on the results of relevant assessments;
6. that relevant professionals and diagnostic services come together to establish agreed AS/HFA and autism assessment procedures; that they ensure continuity by using up to date and agreed diagnostic criteria for the accurate and early identification of classic Autism, Asperger syndrome, and PDD-NOS;

7. that the assessment and service provision functions be independent of each other and that the assessment process is transparently free of any vested interest;
8. that following diagnosis of an ASD, intervention commence within 30 days; that additional assessments as necessary be conducted within 3-6 months.
9. that parents have access to accurate information regarding mainstream and specialised educational options for the placement of their children post diagnosis;
10. that information on a variety of empirically validated methodologies be available to parents; that the values underpinning differing approaches be explored from the professional and parental perspectives before making decisions on educational placements;
11. that Speech and Language Therapy training programmes include a module on differential diagnosis (Language disorder / ASD) so that Speech and Language Therapists may more effectively refer for comprehensive assessment where indicated.
12. That structures for the provision of diagnosis should include arrangements for the early diagnosis of AS / HFA and for the diagnosis and assessment of adolescents / adults with AS / HFA. The importance of early diagnosis of AS / HFA and the equal importance of the availability of assessment for adolescent / adult diagnosis of AS / HFA should be highlighted among the education and health services.
13. That a working group which would include representatives of the Department of Education and Science, the Department of Health and Children, parents and other relevant representatives, be established in each health board region to review the specific needs of people with AS / HFA of all ages in the region..

CHAPTER 5

GENERAL EDUCATIONAL ISSUES

This section will highlight the unique barriers an ASD places in relation to learning, outline a profile for Individual Educational Plans (IEPs), and present other issues that are common to all students with an ASD.

5.1 INTRODUCTION

If children with autism are not given individual attention they may revert to their own repetitive activities or solitary existence (Baron-Cohen 1993, p16).

The nature of ASDs have been described in previous chapters, and it is accepted that it affects the developmental processes of the child throughout life and consequently inhibits learning. In order to provide an effective educational service for children with ASDs, it is fundamental to understand and identify their needs. The chapter is underpinned by two core elements. Firstly the need for closer communication and working practices between those making the diagnosis, parents and educational providers, and secondly, by the recognition that although children with the different disorders on the autistic spectrum are as different from each other as they are from their non-autistic peers, all share a common cluster of underlying difficulties. The Task Force endorses the principle as adopted by the Minister for Education (Press Release, Department of Education and Science, 2000) that, as there is a spectrum of need, there has to be a corresponding spectrum of provision. The following chapters identify appropriate provision across the age and ability continuums. This chapter will introduce the unique barriers an ASD places in relation to learning, outline a profile for a formal statement of need and individual educational plan (IEP), and highlight some of the other issues common to persons of all ages.

5.2 PRESENT STATUS

5.2.1

The submissions to the ATF indicate widespread dissatisfaction with existing services for people with disorders on the autistic spectrum. The consensus of opinion expressed disquiet and mistrust of the current level and quality of provision and approaches to providing adequate educational support and resource; in particular, it was considered that comprehensive and integrated services capable of addressing successfully the needs of people with ASDs in Ireland do not yet exist. In one submission, for example, parents wrote telling how they had sent their child, aged six, to America for an education which they felt was not

available in Ireland. In another submission the parents provided a brief history of their 29 year-old son's life to date, illustrating the frustrations suffered by both child and parents. It was notable that there were only four years in his life which were satisfactory to them; this was when suitable schooling was provided. The parents stated this was a:

...watershed in a 15 year period of total frustration - no formal diagnosis, no understanding, no direction, no facilities..... just get rid of the problem

The same submission commented:

The absence of any dedicated state agency to take responsibility for this deprived section of society in the past is highly regrettable and one can only hope for a more enlightened approach in the future.

Further submissions called on the Task Force to propose a lifelong approach to meeting the requirements of people with an ASD. This point was made by one parents association in the following way:

It is our belief that education continues through childhood into adulthood. We therefore look forward to the Task Force extending its remit to focus on the challenges faced by individuals with an Autistic Spectrum Disorder as they progress through school to further education and supported employment opportunities.

The Task Force empathises with the sentiments expressed generally in the submissions and has attempted to redress the deficiencies of provision within the chapters on early, primary, second, third and continuing educational levels. The Task Force acknowledges the specific implications, for the teachers and parents of children with ASDs, of the impairments in relating to people with ASDs, in communicating with others, and in thinking and behaving flexibly and creatively. The child's, obsessive insistence on sameness, his/her single-mindedness, and extreme narrow interests, combined with the child's difficulty to appreciate others viewpoints and poor social ability to converse with others, substantially challenge educationalists. These facts are major concerns particularly for a teacher who has little background training in relation to teaching pupils with ASDs and is unsure what to expect of the child with an ASD. The outcomes of these difficulties are dealt with in the following chapters but highlighted here in order to indicate the fundamental principles and common strategies which should underlie all approaches and levels of support matched to the needs individuals with an ASD. The Task Force review of a large number of submissions relating to intervention, educational assessment and planning indicates clearly that those who made the submissions consider that educational provision should be based on respect for individual differences, on a broad

spectrum of provision, and on a sound theoretical base and evolving curriculum, assessment and monitoring system. Thirty-eight of the submissions made suggestions regarding what children with ASDs need to learn and how they should be taught. Evidence from these submission can be summarised to reveal a common belief that teaching should meet three requirements:

1. Teaching provision should be developed from a clear understanding of the learning patterns and learning difficulties experienced by children with ASDs.
2. Teachers and others involved in teaching children with ASDs should demonstrate, and be able to implement, teaching strategies reflecting a good knowledge of the main methodologies currently in use.
3. Teachers and others in mainstream classes should be educated in and be able to implement, curriculum adaptations and general accommodations which reflect a clear understanding of the difficulties that may be experienced by students with AS/HFA, PDD-NOS, and Autistic Disorder.

Considerable concern was also expressed concerning the need to provide therapy support across the range of educational settings, particularly, speech and language therapy, as an intrinsic aspect of provision and of the importance of social and behavioural skills within the curriculum provision.

5.2.2

The Task Force's review of the submissions, as well as scrutiny of academic and technical papers, concludes that educational intervention should deliberately reflect the educational implications of ASDs and provide sufficient focus within each school or educational service providing for children with ASDs, on securing:

- a policy indicating whole-school commitment to ASD provision including arrangements to disseminate indicators of good practice;
- arrangements to ensure good quality teaching based on appropriate knowledge of ASDs;
- a breadth of knowledge of teaching approaches and strategies judiciously applied, and
- a child-centred approach to planning, vs a methodological approach.

In securing effective provision, the Task Force proposes that educational planning be based on individually identified need, in the key areas of the triad of impairments, while also addressing the resulting barriers such impairments may impose.

It is also critical to keep under consideration the wide variation among the children and adults with this disorder with regard to both the severity of the ASD and the range of intellectual ability and disability, i.e. from above average to

severely delayed. Although there is considerable overlap in terms of the educational needs of those on the autistic spectrum, the Task Force emphasises that students with AS/HFA constitute a distinct group with certain educational needs specific to their condition. Klin & Volkmar (2000) also stress the need to distinguish between disorders on the autistic spectrum. The Report of the Working Group on Asperger Syndrome (SWAHB, 2001) states that:

Throughout the course of the Working Group's deliberations, the one question, which arose time and again, was how to provide for the similar and particular needs of children with AS / HFA from other children on the autistic spectrum. (p. 36)

and reflects further that:

Looking back over the information the Working Group has gathered over the past three months, two things stand out clearly: a) AS / HFA must be recognized as a condition which in itself, allowing for some ambiguity and uncertainty surrounding diagnosis, warrants special attention and b) basic information on AS / HFA must be disseminated to the key people in the health and social services, alerting them to the symptoms and the condition so that early referral becomes the norm. (p. 36)

5.3 EFFECTS OF ASD ON LEARNING

5.3.1

In addition to the core impairments of social interaction, communication and social imagination and thinking style, there are other difficulties impeding learning and socialisation. Abnormal patterns of social understanding and language expression are particularly common. For higher functioning children, language problems contribute substantially to their social deficits. Over-sensitivity to different sensations, and feeding and sleep peculiarities often interrupt the individual's ability to concentrate and participate effectively in an educational curriculum or programme. It is known that the triad is associated with ability ranging from superior to profound learning abilities, with a susceptibility towards dyslexia and dyspraxia, and with varying degrees of sensory impairments. Affective disorders and seizure activity may, in some cases, also present themselves during adolescence and adulthood. Problems may occur as a result of self-conscious, unusual, or in some cases, challenging behaviours, the possible presence of additional attention deficits, or the effects of peer rejection and social isolation. The effects of such difficulties on learning may be profound. Consequently, in designing curriculum and educational approaches for this population, (children with AS/HFA, autistic disorder and PDD-NOS) the nature of the seizure activity disorders which occur on the autistic spectrum must be well understood and considered every step along the way. It should also be

remembered that children with ASDs are children first and their personality traits and temperament will play a strong role in their attitudes to learning and to learning environment. As a consequence, the task of education is to help individuals with ASDs to make sense of the world around them, and participate more fully in that world. Educational intervention should therefore, acknowledge the distinct differences as well as the similarities between disorders on the autistic spectrum, address the individual needs of the child with an ASD and provide effective means of ensuring the child's access to an appropriate, normalised and normalising curriculum. Children may need to be taught skills which come more naturally to their typically developing peers. Knowledge of the individual's profile of skills and deficits in areas which include learning, communicating, interacting with others and acquisition of adaptive skills is critical as educational strategies cannot be prescribed solely on the basis of diagnostic categories. Teachers, parents and others aiming to teach these children need training in the core aspects of ASDs in order to choose and provide appropriate teaching interventions and secure successful outcomes.

5.3.2

Janzen (1996, p. 23-30) identifies the following problems associated with classic autism. The reader is reminded that these are not true for all ASD children, and are not inclusive. They can also vary in severity not only within the spectrum, but within a given child at different moments in time. The Task Force also prefers an emphasis on communication skills vs language. Nonetheless, these provide a useful guide.

- *The individual is unable to modulate and process or integrate sensory stimulation.*
- *The individual has decreased ability to scan an area or environment to identify and focus consistently on the important elements or events.*
- *Chunks of information that occur simultaneously or very close together in time are quickly associated and remembered.*
- *Information is not automatically or independently organised or analysed to eliminate the clutter, to elicit the meaning, or to determine the relationship of new information to that from past experience.*
- *Information is not retrieved in the correct sequence.*
- *Time concepts and the perception of passing time are impaired.*
- *Language is understood and used literally.*
- *Auditory information is not processed efficiently or reliably.*
- *Meaning is not automatically attached to visual information.*
- *The individual is unable to solve problems and generate new or alternative solutions to fit varied of changing situations.*
- *The individual is unable to totally and automatically control motor (and verbal) responses.*

It should be remembered that special educational needs do not just evolve from difficulties identified during formal assessments. They are also derived from the interaction of a child's strengths and weaknesses with particular environments. The more 'ASD-friendly' the environment and the greater the child's abilities, the less the child's identified difficulties will constitute special needs.

5.3.3

The Task Force recommend the following guiding principles in relation to individual planning for pupils with an ASD. The principles reflect, among others, the best practices guidelines of the Collaborative Work Group on Autistic Spectrum Disorders sponsored by the California Departments of Education and Developmental Services (1997). They can serve as a basis for the creation of standards which should be adopted to secure effective assessment and intervention provision for children with ASD in Ireland. These include:

Principle 1

- individual programmes/education plans will be based on a structured approach and determined by the IEP; a thorough knowledge of ASDs in general, the child and his/her particular ASD is essential;

Principle 2

- individual programmes/education plans will begin at the point of diagnosis and respect the child's strengths and needs; a comprehensive educational assessment and formal statement of needs is required;

Principle 3

- individual programmes/education plans require consistency and varying levels of intensity; family and school collaboration is essential;

Principle 4

- individual programmes/education plans should be continually monitored and evaluated against expected achievements; statutory review and evaluation is central to this.

Principle 5

- individual programmes/education plans will differ from child to child because of the uniqueness of the autistic spectrum disorders.

An important factor in working with, parenting or befriending a person with an ASD is to understand the nature of their disorder. The more we know about how it affects an individual child or adult, the better we can facilitate their learning and our mutual relationship. This can be quite challenging for those working with more than one child with an ASD, as the range of symptomology can vary widely. The degree of severity of the ASD has an impact on the way in which children are taught, the curriculum content, and the context for the teaching.

5.4 CHILD AND ADULT FAMILY SUPPORT AND EDUCATIONAL PLANS; STATUTORY STATEMENT OF EDUCATIONAL NEEDS

5.4.1

Section 4.6.4 of this report describes the recommended Health Board's Child/Adult and Family Support Plan. It is perceived that each child and adult with an ASD that requests support from the Health Board, be in receipt of such a Plan, to be updated as needed or requested. It is further recommended that a formal review of each Plan should be effected at least once every 3 years.

5.4.2

Approximately 25 per cent of the Task Force submissions stressed the need for a systematic educational assessment for each student on the spectrum, leading to an individual plan. Virtually all of these contributions discussed educational planning as taking the formalised structure of an Individual Educational Plan/Programme (IEP). The Task Force has argued the case for a multi-disciplinary model of diagnosis and educational assessment. The evidence suggests the need to develop structures which can secure a child/adult and family support plan and an individual education plan as the most effective means of meeting the needs of persons identified with an ASD. This proposal, if it is to become effective, demands a formal and collaborative working agreement between the education and health authorities. It is widely accepted that positive outcomes are a direct consequence of consistency between the home and the school. The issue for the Department of Education and Science is to consider how best to ensure parental participation in the education of the student with an ASD. In these circumstances, the health authorities, under the auspices of the proposed autism support teams/ASD Intervention Services (or relevant department officials in the interim), should initiate and implement the child/adult and family support plan which will be compatible with a formal Department of Education and Science statement of need.

In addition to the proposed regional Special Needs Organisers who will have a very wide brief, the Task Force recommends the appointment of local ASD organisers to support the work of those at the regional level. They would take on responsibility for the further administration of the provision and arrangements for appropriate school referral, placement, support and scheduling of the formal statement of need and IEP meetings.

5.4.3 Formal statement of educational need

The flow chart under section 4.6.6 of this report suggests the sequence of events that would lead to a formal statement of educational need. The Task Force stresses the necessity of introducing a system of assessment which can be designed into such a statement, to include:

- details of the student's educational needs as identified following statutory, multi-disciplinary assessment and on the advice received from parents;
- the objectives which the provision should address and meet;
- the educational, including supportive therapy, provision which is considered appropriate to meet the needs identified;
- the arrangements for monitoring the progress toward achieving the stated objectives
- timelines for all of the above must be incorporated into the plan.

The Task Force suggest that the proposed Special Needs Organisers (or relevant department officials) should draft educational statements clearly to ensure that teachers and others involved in the implementation of the statement will readily understand what action should be taken to achieve the objectives of the statement. It is essential that the statement be written with full regard for the student's needs, and that resources be found to meet those needs. A provisional statement would ideally be made within 2-4 weeks of receipt of diagnosis, and specify the recommended appropriate placement, subject to review following the outcome of the Statementing process. Placement would then be reviewed on an annual basis. The Special Needs Organiser (or relevant department official), in conjunction with the parents and adult student, when able, arranges for appropriate educational intervention, including school referral(s), educational placement(s) and scheduling of the Provisional Individual Educational Planning meeting. The statutory Statement and Formal IEP would be developed within 3-6 months, and reflect the results of the multidisciplinary assessment described under section 4.8.

Additional consideration of the content and protocols for educational Statementing should be the focus of a working group and should in the Task Force's view, be applicable to children and adults with special education needs generally, with the necessary modifications made to highlight the specific needs of those on the autistic spectrum.

5.4.4 Individual Education Plans

A small number of Task Force submissions from parents whose children had Individual Educational Plans, referred to unsatisfactory experiences related to the development of these. The parents of a four year old boy expressed strong dissatisfaction with several aspects, stating that only one meeting to discuss the

IEP was held in over two years, and in the last five minutes of the meeting, a number of goals were set by the Team with little reference to parents, who were dismissed with little prospect of another meeting to discuss the goals. It is clear from this, and other cited examples, that the Department of Education and Science, in conjunction with parents, should draw up protocols and procedures to standardise the IEP process. The Task Force's view is that IEPs must be directly based on the evidence of assessment and the statement of educational need and must reflect the family and child/adult planning provision. The IEP must address the student's needs resulting from the disability, with the aim of moving him/her towards receiving their education in the least restrictive setting. As such, the IEP should form a document which sets out the different or additional activities from those provided for all pupils and should indicate short term targets and strategies linked to overall objectives and provision as set out in the statement of need. The IEP must direct teaching planning, the teaching approach and resources, be aimed at moving the student towards receiving their education in the least restrictive setting, and act as a review tool to gauge progress. An IEP, to be effective, would include as its main features:

- a brief profile of the student, including learning strengths and concerns
- present/baseline levels of performance for targeted goals
- measurable short term targets, reflecting the student's ASD, which can be achieved in the short term and underpinned by overarching long term goals
- dates for implementation of each goal and objective and date for review
- the teaching strategies and general methodology/ies that will be employed
- support services required to meet goals and objectives, each with a timeline
- when the student will be included with mainstream peers, if he/she is not already;
- strategies for social and academic inclusion
- location(s) in which needs will be addressed
- the expected outcomes
- what accommodations will be made for examinations
- date that transition plan will be developed (to move to next level or service)
- date of formal IEP review
- signature of members of the IEP team, one whom must be:
 - a) a parent or designated parent representative
 - b) special needs teacher, and
 - c) clinician
- procedures to call an interim IEP by any member of the team (which includes parents) should be specified.

During the meeting, the Appeals procedures (section 5.11) should be reviewed with the parents.

The IEP should be jargon free and available to all staff dealing with the student, with a paper copy to the parents. The nature of the IEP should raise the student's

achievements and help him/her, where appropriate, to monitor their own progress. As recommended in the 1993 SERC report:

An education and training programme should be drawn up for each individual pupil and implemented and reviewed on a regular basis;

Arrangements should be made for at least an annual review of pupils with special needs and of the provision being made for them. Parents should be regularly consulted and kept informed.

The submissions to the Task Force indicate that, while the above SERC recommendations on programmes and arrangements may have been implemented for some students with ASDs, they have by no means been implemented for all.

5.5 ONGOING ASSESSMENT

Assessment is an integral part of good educational practice and should inform both curriculum and teacher methodology. In teaching pupils with disabilities, good practice involves a cycle of assessment, programme planning, instruction, record keeping and review. The purpose of assessment is to obtain information in order to plan appropriate programmes, which maximise the learning of each pupil. This approach enables a school to take account of the wide range of abilities, aptitudes and interests that children/adolescents bring to school.

In its recent policy documents and guidelines for teachers, the Department of Education and Science places assessment at the centre of teachers' and schools' work. Every school is required to have a stated assessment policy as part of their school plan. Assessment and the development of individual education plans should be a whole-school responsibility involving the principal, class teachers and any learning support and guidance members of staff. It should be concerned with social and emotional development as well as with academic performance. These considerations apply a fortiori in the case of students on the autistic spectrum.

5.6 UNDERSTANDING AND ADDRESSING BEHAVIOURAL ISSUES

5.6.1

It must be emphasised that there are many students with an ASD who may exhibit unusual, but *not* 'challenging' behaviours and in fact are not considered behaviourally difficult by parents or teachers. Many of the AS/HFA students may not present with any noticeable behavioural difficulties within the educational system. This is reflected in the large numbers of children attending mainstream schools. It is also worthy to note that challenging behaviours may come and go, and do not always occur on an ongoing basis. The term challenging may be defined as follows:

Behaviour can be viewed as challenging if it satisfies one or more of the following criteria.

The behaviour itself or its severity is inappropriate given the individual's age and level of development.

The behaviour is physically harmful to the individual or others.

The behaviour constitutes a significant additional handicap for the individual by interfering with the learning of new skills or by excluding a person from important learning opportunities.

The behaviour causes significant stress to the lives of those who live and work with the individual, and impairs the quality of their lives to a significant degree. (Psychological Society of Ireland, Learning Disability Group, 1998, p. 18)

For those children who do present with difficult behaviour, parents endeavour to manage them through their own experience and intuition, in many cases due to lack of support. Support services are rare indeed in the Republic of Ireland. It is well documented that families with an ASD child experience increased levels of tension and stress (Schopler & Mesibov, 1984; Fitzgerald & Matthews 2000). Likewise children with ASDs may not be able to cope with demands of those who have limited or no knowledge of ASDs.

The reason for a child's behaviour may not be readily apparent. The more we learn about the Autistic Disorders, the more we understand that unusual behaviours and those recently referred to as "challenging" in this population, may be grounded in a very good cause. Our challenge is to understand and respond accordingly.

5.6.2

Significant progress has been made in the field of Behavioural Psychology in the past 15 years. Along with an increased knowledge of ASDs, and direction from parent and professional organisations, a philosophy of Positive Behavioural Programming has been embraced. This requires a solid knowledge base and a co-ordinated and concerted effort on behalf of all involved. Teachers and parents in Ireland are often naturally and culturally drawn to more normalised, child accommodating interventions. Although Ireland has been slow to learn and implement current behavioural principles in some realms, the desire to do so is there, the knowledge is available, and the time is right. This is particularly so in cases where difficulties arise through the child's lack of understanding or failure to develop other more acceptable ways of influencing others and getting needs met. It is important, therefore, to fully understand the function of the behaviour for the child/adult in such cases. This will lead to more effective ways of addressing it. Teaching more appropriate, functional behaviour and supporting the student in behaviour change are principles associated with Positive Behavioural Programming that are proving highly beneficial for those with an ASD who present with behavioural difficulties.

5.6.3 Understanding Secondary Difficulties Associated with ASDs

5.6.3.1

At times some persons with an ASD may have difficulty dealing with the frustrations inherent to their disorder or to society's response to their 'difference'. Sensory, communication, personal and social understanding deficits may, in some cases, result in behaviours which are developmentally and socially inappropriate, and which act as barriers to learning and socialisation. Many adults with an ASD also retrospectively report that they suffered and continue to suffer from severe anxiety, as a consequence of their disability, of not 'fitting in', and/or inappropriate placement or intervention. At times some children and adults with ASDs may engage in outward aggression and/or a marked lack of co-operation. Research has shown that such behaviours may occur as a result of lack of acceptance and/or lack of structure. Poor motivation may be largely attributed to under-stimulation, boredom and/or reduced understanding of circumstances or, indeed, to rejection, loneliness or social isolation. Indeed, where appropriate social inclusion and intervention has been established, the evidence suggests that there is likely to be a significant reduction in such behaviours.

A wide range of behaviours may occur in some persons with Autistic Disorder which challenge them, their parents, teachers, schools and others. These may include fears, anxieties and phobias; eating and sleeping problems; rituals and obsessions; difficulty with transitions; and sensory and physiological arousal problems.

5.6.3.2 Approaches to Facilitate Positive Behaviour

Approaches to dealing with behavioural issues have been evolving over the past number of years. Currently, positive programming is in the forefront. This is the result of a movement towards analysing the function or purpose of behaviours, which has led us to seek to understand *why* someone acts the way they do. It has been found that even the most unusual and puzzling mannerisms and reactions, have a logical explanation in the context of the person with an ASD. All behaviour can be viewed as communicative. The onus is on the non-autistic persons to identify what the person with an ASD is attempting to communicate by their behaviour. All factors possibly related to the behaviour in question are taken into consideration. A profile then typically emerges, allowing for the identification of preventative steps, environmental and instructional adaptations, and to assist the person to better cope with experiences they find difficult or which causes problems for others. Teachers of children with an ASD, and support staff, require training in conducting a functional behavioural analysis so that they might identify and operationally define the behavioural problem, conduct an analysis to determine the cause(s) and maintaining factor(s), determine intervention strategies, and conduct, monitor and revise the teaching plan to

support behavioural alternatives. This procedure might be quite informal in some instances, where by applying common sense and logic, and consulting either with the student and/or significant others, the cause is readily identified and the solution becomes obvious and is easily adopted. Where the behaviour is particularly problematic and not easily resolved, a more formal process may be needed.

Staff should be aware of the importance of consulting all those who work with or live with the person, not least the parents. They also need to be aware that there may not be a simple 'trigger' for a particular behaviour or a simple 'reward' or consequence that is maintaining it. The person with an ASD may build up stress until an otherwise innocuous stimulus can suddenly trigger an unexpected behavioural reaction. The problem then may not lie with that particular stimulus, but with a build up of stress or frustration. This frequently happens in school settings where the able child appears to be managing during the school day but reacts severely to a minor set-back at home or even just to his/her mother's greeting at the end of the day. Indeed, in some cases for children with AS/HFA, the stress of 'pretending to be normal' during the school day, may be significant. Thus the 'cause' of a particular behaviour may not be easily identified, as it could emanate from a set of events over time. A comprehensive behavioural analysis will consider the wide range of circumstances that could possibly be involved. Any clinicians involved, should be consulted during the process of behavioural assessment and intervention planning. A submission to the Task Force outlines the situation thus:

Many children with AS, who experience serious difficulties in the course of their daily lives, learn to 'be invisible', internalising their frustrations and social distress remarkably well in public. Aware that they lack social skills and are unpopular among peers, this group may have little interaction during the school day. They often relax and interact, only in the security of their own homes, where their unusual way of socialising, repetitive monologues on special interests, lack of empathy, insistence on routine etc...are tolerated without ridicule.

Children and adults with autistic disorder could react adversely, e.g. to changes in temperature, lighting or noise that is not even noticed by their carers until a close investigation is completed. Thus regardless of level of functioning, the underlying causation of unexpected behaviours may be easily identified and addressed, or conversely, difficult in one or both respects.

5.6.3.3

Briefly, the formal process of gathering information to use to build effective behavioural support plans is accomplished by identifying the relationship(s) between behaviours that are, in some cases, barriers for the child or unacceptable

to the family, school or community and the physiological factors, and environmental events. Functional Behavioural Analysis is often a repeated or ongoing process.

Functional Analysis = analysing the function or purpose of a behaviour in an effort to understand it.

When we understand the structure and function of a behaviour, we can teach and develop effective alternatives. Functional Analysis helps us to identify:

- any unnecessary situations that prompt the target behaviour);
- new skills to teach that will make the target behaviour unnecessary;
- effective responses to the target behaviour.

Where behavioural difficulties have been identified, the behaviour in question is first clearly identified through a description on which all agree. This includes a baseline measure of intensity, duration and/or frequency. It is then 'analysed' with regard to a variety of conditions and issues, in an effort to determine its function or functions. What motivates the person to do this in this particular way? What keeps him/her doing it? This leads to the development of a behavioural support plan which is undertaken by joint agreement of parents, key personnel, and for the more able, the student themselves. All involved should provide signatures to the agreed plan.

Following the international model for the development of the support plan, a system of measuring the behaviour (data collection) is agreed in such cases, and implemented at specified times by all involved. Reinforcement sampling is conducted to determine what s/he would find pleasurable. These are then used, according to specific schedules, to strengthen appropriate behaviours and reduce inappropriate behaviours along with preventative strategies and other relevant steps to address the issues identified.

Many specific behaviours, particularly in the younger children, can be significantly reduced or eliminated through a well planned and implemented behaviour support plan. This may take a 1:1 or in fact 2:1 staffing ratio for a period of time. It is essential that, where needed, behavioural support be readily available in the classroom and student's homes. The cost : benefit ratio with regard to vastly improving the student's ability to benefit from the educational environment, is great.

5.6.3.4

A formal Behaviour Support Plan typically includes the following components:

- State the target behaviour;
- List the conditions under which it occurs;

- List preventative strategies;
- State schedule of reinforcement and reinforcers and how they will be delivered;
- Reactive strategies;
- How to record the data;
- Review date;
- Frequent review of data (graphed);
- Revision of the plan as data dictates.

5.6.3.5 Understanding Secondary difficulties Associated with AS/HFA

It has been stated that mildness of the ‘handicap’ in AS is what makes its emotional and social impact so severe (Tantam, 2000). Yet the implications of this disorder and the severity of its consequences are significant and well documented throughout the literature. The subtlety of its presentation, under-diagnosis and late diagnosis indicate that although identifiable and overt difficult and ‘challenging behaviours’ sometimes occur within this group, nevertheless, such behaviours are not core characteristics of Asperger syndrome. It is important to stress therefore, that many students with Asperger syndrome do not actually present with ‘challenging behaviours’ but may nevertheless, become extremely isolated and have significant support needs. The behavioural interventions outlined in this chapter, therefore refer to those with ASDs and additional behavioural difficulties.

As with any population, some children with an ASD may also experience a psychiatric or emotional disorder. This is particularly true during adolescence. Higher functioning and Asperger’s Syndrome teens are particularly vulnerable to depression and anxiety, which may arise because of social failure, bullying, victimisation, and marginalisation by peers, etc. Research in other countries has shown that up to two-thirds of students with Asperger’s Syndrome are bullied at school (Tantam, 2000). It is important, therefore, to acknowledge that typical peers often display a high degree of intolerance and, at times, challenging behaviours towards children with AS/HFA. Whole school plans must implement effective educational and reactive strategies in this regard (Rogers, 2000).

For most individuals with AS, (and HFA) the most important item of the educational curriculum and treatment strategy involves the need to enhance communication and social competence. This emphasis does not reflect a societal pressure for conformity or an attempt to stifle individuality and uniqueness. Rather, this emphasis reflects the clinical fact that most individuals with AS (& HFA) are not loners by choice, and that there is a tendency, as children develop towards adolescence, for despondency, negativism, and sometimes, clinical depression, as a result of the

individual's increasing awareness of personal inadequacy in social situations, and repeated experiences of failure to make and/or maintain relationships (Klin & Volkmar, 1996 p. 7-8).

Clearly, the social and emotional needs of persons with ASDs constitute a critical issue across the range of education provision, training, and prospective employment opportunities. ASD specific/learning disability education provision and sheltered continuing education/training/employment projects routinely take such needs into consideration as core components of their curricula and training services. However, to date, there has been little recognition of such needs among those persons with AS/HFA who are outside the remit of such provision. This situation has placed an intolerable burden on parents who are the primary service providers (by default) for this group. The absence of dedicated late adolescent/adult AS/HFA specific support services and interagency support structures is a source of continuing concern in this regard. The consequences of long-term social isolation, marginalisation, peer rejection and stress related anxiety, on the self esteem of many self-aware individuals with AS/HFA who may be at home without any service provision, or participating in mainstream education and training courses have been overlooked entirely. The perceived quality of life of adults with Asperger Syndrome was examined by Craig (1998), who reported that adults in his study valued and desired friendships more than anything in their lives. This research, and the submissions to the Task Force, indicate that social exclusion and, in turn, isolation are potentially damaging and common problems for young people with AS/HFA. Accordingly, it is the view of the Task Force that all persons diagnosed with AS/HFA should have access to age-appropriate social, communication and life skills training programmes across the range of educational settings; that where diagnosis is made during adolescence / adulthood, intervention programmes i.e. peer support groups/ social understanding initiatives should be implemented immediately.

5.6.3.6 The failure of individuals with Asperger Syndrome to develop relationships may be met with social stigmatisation and a lack of support and rejection, which can lead to other consequential secondary disabilities (Tantam, 2000a). Although some individuals may lack insight into their difficulties, many are acutely aware of their shortcomings and deficits in social integration (Attwood, 2000). Despite experiencing serious difficulties in the course of their daily lives, they often strive to 'be invisible', internalising their frustrations and social distress remarkably well in public. There is a tendency for many of this group to withdraw to the security of 'special interests'. They are also often isolated and under unremitting stress as a result of 'not fitting in'. There is evidence (which is supported by parents) that adolescents/adults with Asperger Syndrome often go to great lengths to mask their deficits (Carrington & Graham, 2001; Willey, 1999). There is a risk that the stress associated with this 'masquerading' may lead to depressive symptomatology (Szatmari, 1991; Williams, 1995; Attwood, 2000). People with AS and others may attribute the disorder to a moral defect because of the subtle and seemingly mild

presentation, and the emotional consequences of the disorder affects outcome to a greater degree than has been commonly recognised (Tantam, 2000a).

It generally follows that the more intelligent the person, whether or not they have an ASD, the more able they will be to understand and manage situations. However, for some people with an ASD, and, particularly those with Asperger's Syndrome, being of average or above intelligence might lead to an increased awareness of their difficulties and increased anxiety and distress which will then disrupt their functioning. In some cases, they may have succeeded well academically, gaining university degrees or other qualifications, but nevertheless may require support in their everyday lives to live happily and successfully. They may live independently but have regular contact with a support service or they may need to live and/work within a supported community or with their family (Jordan et al, 1998 p. 17).

The predisposition of this group to affective/ psychiatric disorders has been well documented, with depression and anxiety disorders being particularly common (Attwood, 1998; DeLong *et al*, 1988; Gillberg, 1985; Clarke *et al*, 1989; Tantam, 2000b; Howlin, 2000; Wing, 2000). Surveys into the suicide rate in Ireland have established the need to be aware of the warning signs of suicide. Depression, rejection, isolation, and the loss of hope, it is agreed, are major contributing factors in both para-suicide and suicide. A significant number of adolescents / adults with AS / HFA also suffer from depression, isolation, loss of hope, rejection, low self esteem and suicides have been reported among this group. Although regional health boards initiate 'suicide prevention campaigns' aimed at specific target groups, many people with AS / HFA are without access to social/community integration opportunities, intervention services, counselling or support. Without a social structure to their lives, many are unmotivated; their lives may be dangerously empty. A submission to the Task Force outlines the difficulties experienced as follows:

5.6.3.7

People with AS / HFA can learn socially acceptable behaviour patterns and many also have the capacity to do well academically if supported to do so..... Because this group have difficulty understanding the intricacies of reciprocal interaction and are confused by normal social cues, their efforts to 'fit in' very often meet with failure. In this situation, daily life can become an enormous struggle with severely limited opportunities for normal levels of participation in many aspects of community life. Age/awareness appropriate support is seldom given sufficient consideration. The struggle and depth of self-awareness of some older children and adolescents is often underestimated.... Many adolescents are terrified of being singled out and further

stigmatised by being seen to need support. They are often desperately trying to 'fit in.' Support for this group should be discreetly arranged on a confidential basis.

Persons with AS / HFA are extremely vulnerable in any situation where their naiveté and the extent of their social and communication difficulties are not adequately recognised and are more likely to be the victims rather than the perpetrators of aggression (Tantam, 2000a). Nevertheless, although the vast majority of those with AS are unusually conscientious and unwilling to break the law, isolated incidents of lawbreaking may occur in situations, which the person feels, are justified. Where such difficulties arise (e.g. in the context of innocently pursuing a special interest or being 'set up' by peers etc.), lack of empathy and social interaction deficits may exacerbate the situation. It is, therefore, important that the Gardai and Probation Service should be aware of this condition and respond to it sensitively. Awareness of the vulnerability of persons with AS / HFA (an indeed, all ASDs), is critical and protective strategies and support services are likely to be needed throughout most mainstream and sheltered environments.

5.6.3.8

The issues outlined above have significant implications for the way in which future education and intervention/community support services for adolescents and adults with AS / HFA are identified and delivered in Ireland. This is particularly relevant in the mainstream context; where there is currently little shelter or support, and the social pressures faced by this intellectually able group can be significant. Issues that need to be addressed include:

- social inclusion;
- socialisation;
- positive mental health strategies;
- community integration (e.g inclusive recreational opportunities, physical fitness regimes through local gym membership, special interest clubs, social understanding groups etc.);
- confidentiality regarding disclosure of disability status among peers;
- counselling with a particular focus on social interaction difficulties;
- maintaining links with parents.

Clearly, access to meaningful and inclusive leisure and social opportunities will be relevant to the well being of many of this group. Joint interdepartmental responsibility will again be necessary to provide an adequate level of support. The learning, and support needs of each individual, therefore, should be identified by careful consideration of associated factors, which may impinge on the individual's ability to learn, function and achieve an acceptable quality of life. Support and intervention should not be deemed applicable on the basis of knowledge informed by diagnostic labels or by assumptions that a 'one size fits

all' approach to education/intervention is appropriate or acceptable, but by the identification of individually assessed needs. These issues should be prioritised and funded for persons in the 'mainstream' who are without a dedicated service provider just as they are routinely prioritised within autism specific/learning disability service provision.

Extreme caution should be exercised when deciding who should be informed about the diagnosis of Asperger Syndrome (Attwood, 1998a). The dignity and decision of each person regarding disclosure / non-disclosure of disability status among peers should be respected (Wing, 1996).

5.6.3.9 Behavioural Guidelines

There are reasons that some people with an ASD find it very difficult at times, to inhibit their behaviour. It is not effective, therefore, simply to forbid actions. Staff should be aware that the behaviour, may or may not be intentional, but nonetheless may be connected to the disability.

There will be a small number of students from pre-school through continuing education levels that are either not ready for or able to be successful in the classroom environment. Highly individualised programmes, both at home and school, will be required to facilitate their educational needs. These should be co-ordinated and funded by the Department of Education. The objective should always be to carefully enable these students to make the transition towards lesser restrictive, more normalised settings as quickly as possible.

No student should be suspended or expelled from their educational programme due to behaviours resulting from the severity of their disability. The Department of Education and Science must develop procedures to accommodate these children whilst simultaneously supporting their staff who are charged with educating them. A range of options should be established and offered to the student, school and parents for those periods when the child is not coping sufficiently with their assigned class or programme. Even with a maximum level of support, it must be acknowledged some students will best be supported primarily in a professionally staffed setting, either residential or day. A submission to the Task Force states:

The parents of many autistic people wish them to live in harmony within the family and should be given every assistance to make this possible. If the difficult decision has been reached that it is not possible or suitable for the person with autism to live in the family

home ... the State should help and not hinder parents in this very difficult position.

Other submissions referred to the need for a continuum of residential provision ranging from autistic specific five day boarding schools to a seven day, full time residential programme.

5.6.3.10

It is beyond the scope of this document to define specific behavioural guidelines in detail, many of which are readily available in print. Autisme-Europe's global criteria are included in Appendix 7. Their emphasis is on preventative and non-aversive interventions and this approach is supported by the Task Force. A document: *Responding to Behaviour That Challenges* (1998), is available through the Psychological Society of Ireland and should be referenced by all programmes working with children and adults with ASDs who have additional challenging behaviours, and in particular with those who have an accompanying learning disability. It emphasises the need for multi-element, individualised behaviour support plans, properly sequenced and implemented, following consultation with *all* persons to be involved. Parent permission for the plan should be secured and a review process must be included in the plan. The Department of Education and Science should consider establishing a system whereby senior staff (or, in the interim, consultants) well versed in both ASDs and behavioural intervention, review the initial written plans and subsequent data, to insure best practice.

The Department of Education and Science, in conjunction with the health boards, voluntary/non-governmental organisations, and parents, should establish very clear behavioural guidelines for all staff to follow in cases where behavioural difficulties have been identified. A working party to review existing policies and reach a consensus should be established. This is a matter of urgency as some children are being physically and/or chemically restrained, and some suspended and/or excluded from educational and other programmes, and/or transport. In addition to 'routine' approaches where there are identified behavioural challenges, Crisis Management Procedures must also be specified.

The Child Protection Act, including mandatory reporting must be followed in all relevant instances. The Educational Welfare Act requires schools to have published codes of behaviour. There is, however, no reference in this Act to students with disabilities. This will need to be remedied to insure school policies are put into place for those with disabilities.

5.7 Behaviour Specialist Posts & Behaviour Support Teams

5.7.1

Posts designated as ‘behavioural support’ need to be established in both the Department of Education and Science and the Department of Health and Children. Behaviour specialists and behavioural psychologists should be employed to support the education of children with ASDs, where necessary, and the classrooms to which they are assigned in those cases. In all settings, those involved with children with an ASD should receive instruction in the complex understanding of and use of the principles of Positive Reinforcement.

5.7.2

It is further considered that Behaviour Support *Teams* be established in each region, to be called into homes and schools when efforts to effectively deal with difficult behaviours have been unsuccessful. The team would conduct a full assessment around the presenting problems, design an intervention plan, then initiate the plan while simultaneously training staff and family members to take over. Phone support could subsequently be provided to modify the programme as the data dictate.

5.7.3

Training and support for staff, peers and family members who are distressed as a result of another’s challenging behaviour are also required. Medical care and counselling should be available to those affected by ongoing exposure to difficult behaviours. Procedures for accessing these supports must be specified to facilitate access.

5.8 THE ESTABLISHMENT OF A VISITING TEACHER FOR ASDs SCHEME

5.8.1 Visiting Teacher Service

It is indicated elsewhere in this Report that the conditions grouped under the heading of Autistic Spectrum Disorders are complex, and that individuals with ASDs will be appropriately placed in a variety of different educational settings (as outlined in Chapters 7, 8 and 9). It is also argued throughout this Report that provision of information and awareness for professionals is imperative, as is education and training in ASD-specific interventions and methods. There is, consequently, a need for flexible and accessible mechanisms in the delivery of service to children with ASDs, from time of diagnosis and for the duration of the child’s schooling. Throughout this Report a range of recommendations are made with regard to the education of the child. A critical issue to be addressed throughout the child’s educational progression from one level to another, or from one type of school or setting to another, is that of continuity. In order to provide such continuity, and to provide a fund of expertise for the benefit of teachers working in schools with the student with an ASD, the Task Force recommends the

establishment of a Visiting Teacher Service for children with ASDs. This Service could build upon an existing model – the Visiting Teacher Service.

The Visiting Teacher Service was established in the Department of Education and Science in 1972. Originally it catered only for children with hearing impairment and visual impairment but was extended subsequently to include some additional disabilities.

Currently it is managed by the Inspectorate of the Department of Education and Science. The Visiting Teacher Service for Children with Certain Disabilities consists of forty-two teachers who are based throughout the country, each with responsibility for a disability category or categories in an agreed geographic area. Each of the Visiting Teachers has undergone basic teacher training and has received additional training and development in his/her particular area of responsibility. The Visiting Teachers of the Deaf, for example, will have received the Diploma for Teachers of the Deaf (UCD) and will have had experience as teachers of deaf children. They will also have had training in other relevant areas such as counselling.

The role of the Visiting Teacher can vary somewhat, depending on the disability, the level of need and the requirements of the family. A particular feature of the service is the degree of flexibility which exists in the organisation of the service in each particular case. This means that the service can always be designed to meet the particular requirements of the pupil/student and his/her family.

The Task Force believes that the support role of the Visiting Teacher provides a model that would be applicable and very appropriate in addressing a crucial area of need in the case of children with ASDs. It would, of course, require a high level of knowledge and understanding of autistic spectrum disorders, as well as substantial education and training in the principal methodologies appropriate to ASDs, for those appointed to the Service.

At present, when a child is diagnosed with a relevant disability, the case is immediately referred to the Visiting Teacher Service. The Visiting Teacher then visits the child and the family in the home. From that point onwards the Visiting Teacher is available as a support to the family. He/she counsels the family and, in the case of deaf children, advises on the management of equipment and on the development of language and communication skills. Home visits take place by mutual agreement on a regular basis. The frequency and intensity of the involvement of the Visiting Teacher depends on the particular needs and circumstances of the individual child and family and on the size of the teacher's caseload. The Visiting Teacher may also become involved in direct teaching of the child, as appropriate, even from an early age. However, the main purpose of such interaction with a very young child may be to support and guide the parents in their management and promotion of their child's learning and communication and in their support of the work of the school or pre-school in question. In

addition the Visiting Teacher discusses with the parents the other supports available and makes them aware also of the range of educational options available at any time and advises on appropriate action in this regard.

The involvement of the Visiting Teacher normally continues throughout the career of the child in mainstream education, including pre-school. The Visiting Teacher continues, in agreement with the parents, to visit the child at home and at school on a regular basis, providing advice and guidance on the education of the child and providing an important link between the school and the home. As well as providing support of this kind to parents, the continuing role of the Visiting Teacher, both at home and at school, includes advice on appropriate educational objectives and on the evaluation of progress. It also continues to involve direct tuition as necessary, in agreement with the parents and in close consultation and co-operation with the mainstream teacher and other support teachers (such as the learning-support or resource teacher). As part of his/her role the Visiting Teacher also liaises with professionals and with other agencies, as necessary.

In terms of interfacing with other special educational services, particularly as the child moves into different settings, the underlying approach is that the Visiting Teacher remains as available as is necessary. For example, if a deaf child goes to a special school for children with such disabilities then the role of the Visiting Teacher decreases, on the assumption that there is a high level of expertise in that special setting and also on the assumption that there is a high level of home/school contact already in place as part of the overall plan of such a school. If, on the other hand, the distance from the home to the educational placement (perhaps residential), or other circumstances, were to demand it, then the Visiting Teacher's role could continue to be an important link.

The Task Force regards the role described above as having real relevance for children with autism, particularly in the early years. Such a service could then dovetail with the other support/advisory services that would come on stream as the child advances through the system.

The Task Force recommends, therefore, that a Visiting Teacher Service, similar to the Visiting Teacher Service for children with impaired hearing and with a high level of very specialised training in the area of Autistic Spectrum Disorders, be put in place for children with ASDs.

5.9 PARENT - SCHOOL PARTNERSHIP

Throughout this report, the absolute necessity of including and supporting parents each step along the way has been emphasised. Please refer to chapter 3 which outlines the Task Force's suggestions to strengthen the partnership between parents and schools.

5.10 APPEALS PROCEDURES

Parents in Ireland to date, have had to have access to the court system where there was disagreement on placement and service provision issues. If the recommendations in this report are implemented, it is anticipated that differences between the parents of students with an ASD, the Department of Education and Science and the Department of Health and Children would be infrequent. On those occasions where a consensus cannot be reached at the ground level, a formal, independent, incremental system of appeal must be developed (see Chapters 4 and 14). It must be speedy, easily accessible, and democratic. When needed, parents should be provided with an advocate to assist them through the procedure, or upon their request, represent their interests. There are a number of school systems in the United States, England and Northern Ireland that have developed such procedures. These should be investigated by the Department of Education and Science in their development of a comprehensive appeals process.

5.11 RESOURCES

The need for capital resources, along with equipment, materials, staffing, training, transportation, etc. will be addressed in other sections of this Report. Additional resources would include, for example, administrative support for schools initiating a special programme or set of support services for one or more ASD children. This could take the form of informational material and a list of persons they could access for advice and to secure the entitlements for the child, approval of school level administrative support, etc. A resource pack of materials for teachers in all sectors of the educational system, at all levels, public or private, should be provided as needed for each category of ASD children being served. This would include curriculum guides, information on the disorder, academic material, social training programmes, community resources, integration options, web sites, etc. Particular reference to the formal Statementing process and development of Individual Educational Plans will create the need for significant training for the general school body (see Chapter 12 on Staff Education). Responsibility for insuring all of the above, would lie with the Special Needs Organisers which have been recommended by the Department of Education and Science *Report of the Planning Group: A National Support Service for Special Education for Students with Disabilities* (2000), which recommendation is supported by the Task Force.

5.12 RESEARCH

There is a scarcity of educational research on ASDs in Ireland generally. Systematic study of the following areas is required:

- methodologies and approaches
- the benefits of various clinical interventions
- development of ASD-specific components of teacher and classroom assistant training

- research-based curricula
- inclusion in education
- strategies for successful mainstream education
- systematic evaluation of all pilot projects

It is deemed essential that formalised Department of Education and Science/ University partnerships be established well beyond those which exists for basic primary teacher training. The ensuing research activity would focus on the issues raised in this Task Force Report.

5.13 RECOMMENDATIONS

The Task Force recommends:

Policy

1. that the Minister of Education recommend to the Minister of Health and Children, the introduction of Statutory Child/Adult and Family Support Plans for those with an ASD;
2. that the Department of Education and Science, in collaboration with parents, the Health Boards, and relevant voluntary/non-governmental organisations, develop behavioural guidelines for staff and that these guidelines be distributed to all schools and institutions catering for persons with ASDs;
3. that no student should be suspended or expelled from their educational programme due to behaviours resulting from the severity of their disability;
4. that schools and programmes educating one or more students with an ASD are properly resourced;
5. that formalised Department of Education and Science-University partnerships be established to develop appropriate programmes for persons with ASDs;
6. that a Visiting Teacher Service, similar to the Visiting Teacher Service for children with impaired hearing and with a high level of very specialised training in the area of Autistic Spectrum Disorders, be put in place for persons with ASDs;

Practice

7. that the Department of Education and Science instruct and resource the In-Career Development section of the Department to prioritise the training of all staff involved in the education of students with ASDs to insure their understanding of how the particular ASD and any accompanying disorder affects the student's learning style;

8. that schools providing for persons with ASDs implement the Statementing procedure and detailed individual education plans which respond to the needs of the child and provide for education in the least restrictive setting;
9. that extreme caution be exercised when deciding who should be informed about the diagnosis of Asperger Syndrome, and that the dignity and decision of each person regarding disclosure / non-disclosure of disability status among peers be respected;
10. that the marginalised lifestyles and social isolation of those with ASDs be acknowledged through pro-active policies that promote social inclusion, positive mental health and community integration; that such strategies be prioritised and funded for late adolescents/adults with AS/HFA in the 'mainstream' who are without a dedicated service provider and at risk of social isolation/depression through lack of social opportunities;
11. that the Department of Education and Science introduce Behaviour Support Teams in each region to support the education of children with ASDs and additional behavioural difficulties;
12. that a range of suitable options be developed, so that students presenting with significant behavioural challenges will remain in a suitable educational programme, un-interrupted, while simultaneously supporting the staff who are charged with educating them;
13. that all persons diagnosed with AS/HFA have access to age-appropriate social, communication and life skills training programmes across the range of educational settings; that where diagnosis is made during adolescence / adulthood, intervention programmes i.e. peer support groups/ social understanding initiatives should be implemented immediately;
14. that Gardai and Probation Officers be aware of AS / HFA and respond to it sensitively; that it be part of pre-service training at Templemore training college, and part of inservice training in the Probation Department;
15. that research be carried out on methodologies and approaches; on the benefits of various clinical interventions; on the development of ASD-specific components of teacher and classroom assistant training; on curricular interventions; on inclusion in education for persons with ASDs; on strategies for successful mainstream education; and that there be systematic evaluation of all pilot projects.

CHAPTER 6

EDUCATIONAL APPROACHES

6.1 INTRODUCTION

There are two major issues in the provision of education for children with ASDs. The first is each child's entitlement to a curriculum suited to his/her needs and abilities and how the child can gain access to that curriculum. The second is the role of education in the efficient fostering of learning and skills which also accommodate the personal and social development of students with ASDs. This Chapter addresses the latter concerns.

The kinds of methodology that may best serve the learning and developmental needs of children and young people with ASDs was discussed in twenty seven submissions. As well as attracting a good deal of comment, several academic and technical papers were submitted. Numerous submissions emphasised the importance and outcome of methods of Applied Behaviour Analysis, with some parents requesting this and others stating their satisfaction with this approach. The principle of inclusion was also prominent, together with the principle of making provision in the least restrictive environment. Others requested provision for their children to be with others of similar age and ability. The various placement options will be presented for early, primary and secondary levels, chapters 7, 8 and 9.

The Task Force on Autism agrees with the concept that:

...the diagnosis of autism does not and should not lead to a specific set of educational strategies (Strain, et al, 1998).

This implies that the individual needs of the student are paramount, and that these will differ from one person with an ASD to the next. The Task Force also advocates that the specialist approach or approaches be based on the student's current presentation. Thus there may be times or conditions under which a singular, selective approach may be exclusively or almost exclusively used with a child, and others when a combination of approaches will be preferred.

The Task Force supports the objective of the Education Act (section 6F) to 'promote best practice in teaching methods with regards to the diverse needs of the students and the development of the skills and competence of the teachers'.

A variety of teaching methodologies are particularly associated with ASDs. Many are supported through anecdotal reports, few through controlled research studies. A very simplified and brief reference to these are included here. Interested readers are

encouraged to access relevant publications and training workshops to become fully informed on any one approach.

6.2 Various Specialist Approaches and Treatment

6.2.1

Teaching approaches that have been researched and reported as not having a beneficial effect include:

- Facilitated communication, where the person with an ASD is ‘facilitated’ through sensitive touch to their hand by another person, to type out their thoughts and feelings. Most research indicates the typing is unconsciously authored by the facilitator.
- Auditory Integration Training, where the child attends a program for approximately ½hour twice daily for one - two weeks, is exposed to various sounds, pitches and volume through headphones. A recent study by Mudford and colleagues (2000) demonstrated that a placebo condition of wearing headphones alone was just as effective.

6.2.2

The following approaches have poor or no outcome research (Heflin and Simpson, 1998):

- Holding Therapy, where when the child does not give eye contact, the adult holds the child tightly until calm returns and eye contact is established; based on the belief that autism results from a broken symbiotic bond between parent and child.
- Options Insitute/Son Rise which advocates a 1:1 home-based approach where the child is followed by a ‘mentor’, particularly the parent, who tries to enter and understand the child’s world in an effort to entice the child eventually to interact. The child may spend months or years in the designated room, without interacting with the ‘outside world’ which is perceived as a cause of distress. The adults accept the child and his/her actions fully. (An incidental but important benefit of this approach has been that parents finally feel ‘heard’, as when the child is with various staff members, the parents are meeting with the programme co-ordinators, for up to eighty hours in the one-two weeks of orientation.) The program itself has not been evaluated.

6.2.3

The next group have a research base, with mixed reports, i.e. both supporting and neutral results:

- Sensory Integration Therapy (SI), which is primarily the realm of Occupational Therapists. SI refers to the organisation among the various senses (vision, hearing, taste, touch, smell). As the ability to take in, sort out and connect information from the world via the nervous system is impaired in persons with an ASD, SI therapy engages them in play and physical activities that are designed to integrate the nervous system, resulting in improved overall functioning. Anecdotal reports on SI are very positive but more formal research is required.
- Vitamin Therapy, particularly B-6 and Magnesium. Some persons with ASD are found to improve their attention and hence learning and behaviour.
- Dietary Program to alleviate the effects of food intolerances in individuals with ASD associated gastro-intestinal disorder. Some parents find that the removal of gluten and casein, such as wheat and dairy products, from the diet can improve symptoms of Autism, but further research is urgently required. (Shattock, 2001)
- Higashi Approach: Daily Life Therapy, where the children are continuously involved in group activities, particularly motor activities and physical training, up to sixty hours per week. There are no satisfactory published results, however benefits may be expected due to the high degree of structure, long hours and strong physical sensory input.

6.2.4

Some relatively new approaches have not yet been subjected to rigorous scientific research, but were in fact developed from research. These include:

- The Miller Method, a cognitive-developmental systems approach emphasising body organisation, social and communication issues;
- Functional Developmental Individual Difference Relationship-Based Approach, Stanley Greenspan, M.D. This is based on following the child's lead, semi-structuring designated problem-solving interactions, and sensory/motor/spatial activities. It targets interpersonal interaction (emotional versus cognitive development) and integrated developmental skills. It is also known as 'floor time'.

6.3 Main Approaches

Dawson and Osterling (1997) reviewed 8 different early intervention programmes for 150 children with autistic disorder and pervasive developmental disorder-NOS. The children received 15-40 hours of programming weekly, and found that though not directly comparable due to varying approaches and philosophical differences:

...all of the programs were quite effective in fostering positive school placements, significant developmental gains, or both for a substantial

percentage of their students. Of the six programs that reported placement data, four reported that approximately 50% of children were able to be integrated into a general classroom by the end of the intervention. When outcome was assessed in terms of I.Q., it was found that children made, on average, an I.Q. gain of approximately 20 points... (p. 314)

There are two main approaches, both included in the above referenced review, which have undergone numerous studies and have been found to result in progress in learning and a decrease in autistic behavioural characteristics:

- 6.3.1 **Applied Behaviour Analysis (ABA)**, which is a theory of learning based on an understanding of a behaviour or set of behaviours, the breaking down of the components of the tasks involved in learning, and the application of consequences to either reduce/weaken or increase/strengthen a particular behaviour or set of behaviours. ABA is utilised in various ways in a multitude of settings, e.g. organisations, marketing, parenting, mainstream and special education and training. *One* manner of application is its concentrated use commonly referred to as the ‘Lovaas Approach’, after its original proponent, Ivar Lovaas, UCLA. This approach has been in use for nearly 30 years with very young children with autistic disorder. Presently, there are numerous variations on this, e.g. those that are proponents of ‘precision teaching’, ‘pivotal response training’, ‘incidental teaching’, and those that continue to follow ‘discrete trial teaching’. The theoretical base is Behavioural, based on operant reinforcement principles. There are a significant number of published studies, more so than any other approach, following experimental designs, which support positive outcome (Lovaas 1987; Kazdin 1993; Koegel & Frea 1993; McEachin et al 1993). ABA is a highly formalised method of 1:1 instruction and at times, 2:1. Based on an assessment of current skills, numerous systematic instructional sequences, are presented to the child, with correct trials resulting in positive reinforcement. Progress is very closely monitored through recording of the child’s reaction on each trial throughout the day, and then graphed for reference as to when to move on or modify procedures. Originally forty hours per week of instruction in a university clinic were advocated, though most students are now accommodated in their homes, outpatient or specialist clinics, and schools. ABA is advocated to be initiated primarily, but not exclusively, with children under age four. Subjects of related studies are reported as meeting the diagnostic criteria for Autism, with no mention of Asperger’s Disorder, thus its use in the manner described in these studies, i.e. frequent, repetitive drills, has not been demonstrated for this population. This should not, however, discourage teachers from following an ABA procedure for designated learning tasks, when indicated, with students with AS/HFA.

A classic study reported by Lovaas (1987) prompted critical reviews at the time and continues to be hotly referenced, supported and refuted within the field of autism intervention. Mild aversives were used in the original study, but are no longer advocated or supported. Other researchers (e.g. McEachin, et al, 1993;

Sallows and Graupner, 1999) have conducted similar studies, without aversives, and similarly report marked improvements in nearly half of the children involved.

6.3.1.2 Variations on Lovaas' original teaching paradigm are somewhat prolific. However, upon review for this report, it was found that they are still basically the same as they were in the early 1970's reflecting the efficacy of operant conditioning in teaching children with autism. In practice, some schools which present as 'ABA' today, actually make use of music, group social skills, and communication programmes such as the Picture Exchange Communication System in their day. This is a welcome complement to the table top drills and compliance training which characterised a 'pure' approach.

The Autism Society of America states the advantages of the approach as giving the child a good beginning in the skills needed to learn, e.g. attending, imitation, receptive and expressive language, pre-academics and self-help. They cite as concerns:

...no differentiation for subtypes when creating curriculum; emphasised compliance training, prompt dependence; heavy focus on behavioural approach may ignore underlying neurological aspects of autism, including issues of executive function and attention switching; may over-stress child and/or family; costs...prohibits equal access...interpreting all behaviours as wilful; ignoring sensory issues or processing difficulties... (Autism Treatments, www.autism-society.org).

In their *Clinical Practice Guidelines for Early Intervention* (1997), the New York Department of Health recommend that 1:1 direct systematic instruction in intensive behavioural programmes include a minimum of 20 hours weekly in addition to parental/home intervention.

Those implementing the ABA teaching approach, must undergo supervised training from professionally qualified behaviour analysts, and other than those at the postgraduate level, continue to receive a hierarchical level of on and off-site supervision of their work. The systematic recording of the child's achievements inherent to ABA programmes, is an important exemplar to be followed for all planned interventions.

6.3.1.3 In Ireland there are a number of ABA professionals who provide training and supervision to individual children and parents, and to ABA specific home/school programmes. Some of the teachers in classes for children with an ASD received a one day introductory training only in ABA theory and procedures, with no follow-up available. At least one of the Health Board ASD teams (SWAHB) has ABA trained professionals employed as project workers who apply the principles of applied behaviour analysis to their work with children and families.

Studies on the ABA method of intensive intervention with young children with autism continue to be the subject of peer review controversy (Schopler, et al 1989; Lovaas, et al 1989; Huber 1991; Bristol et al 1996; Gresham et al 1997; Shreibman 2000; Heflin and Simpson 1998). Such discussions contribute to the closer scrutiny of all approaches and remind us once again, that there is no one intervention accepted by all parents and professionals above all others.

6.3.2 TEACCH : (The Treatment and Education of Autistic and Communication Handicapped Children) programmes have also proven their effectiveness in early childhood and beyond (Short 1984, Mesibov, 1994, 1995, 1996, 1997; Ozonoff & Cathcart, 1998). The basis of the TEACCH approach is an understanding and consequent response to the person's ASD. It considers the need for lifelong support and has this in mind when designing programmes with a focus on developing independent 'work' skills from pre-school age. TEACCH is based on a system which provides clear, concrete, meaningful visual organisation along with a high degree of structure and progressive independence within the classroom and environs. It organises the classroom (space), the day (time, routine), and the activities (pace & duration). Tasks are chosen following individualised assessment in eight skill areas and goal planning, taught primarily in functional contexts and are structured in a highly predictable manner, referred to as 'structured teaching'. It continues to evolve over time, taking research from other fields, e.g. Occupational Therapy, Neurobiology, into consideration, and can incorporate other strategies, e.g. PECS and ABA. Programme evaluation outcome studies for general learning and life skills in relation to children with autistic disorder are good.

TEACCH has been implemented and investigated for over 30 years, initially in the State of North Carolina, U.S.A., under the direction of the University at Chapel Hill and more recently in European countries (Durnik 1996; Sines, et al 1996).

6.3.2.2 The Autism Society of America (Autism Treatments, www.autism-society.org). notes the following advantages of the TEACCH approach:

..dynamic model; anticipates and supports inclusive strategies; compatible with ... selected therapies; addresses sub-types of autism ...; identifies emerging skills, with highest probability of success; modifiable to reduce stress in child and/or family.

Their concerns include:

...belief that TEACCH 'gives in' to autism ...; seen by some as an exclusionary approach...; does not place enough emphasis on communication and social development; ... treating TEACCH as a single

classroom approach rather than a comprehensive continuum of supports and strategies ...

TEACCH also has a formal training protocol, conducted by certified trainers, and requires frequent updating of staff by professional advisors. In Ireland, basic TEACCH training has been provided to many of the teachers of children with ASDs, but the necessary supervision and further training, has not occurred. Consequently, some of the principles and teaching strategies associated with TEACCH are in use, but the 'formal' TEACCH programme is not.

6.3.3 Dawson and Osterling (1997) describe TEACCH as emphasizing:

...two basic principles: structuring the environment to promote skill acquisition and facilitating independence at all levels of functioning...one to one instruction is offered...gradually gaining increasing independence... The TEACCH program, which strives to provide the least restrictive teaching environment, is used throughout North Carolina in a variety of different school settings and in a variety of different ways... (p. 310)

The organisational systems inherent to the TEACCH approach appear valuable for relevant teachers and many of the children, particularly those with below average intellectual functioning. There are some concerns that this approach may be of limited value to high functioning students with ASDs as a submission to the Task Force expressed:

Suddenly, M. has been forced to learn by the TEACCH system - child that can talk and communicate now has to learn with visual cues! It's a well known fact that autistic people can regress and un-learn anything they have previously learnt-this certainly is a good way to go about it. M. will not do well if this system is continued. She needs something else but no-one is trained. Teachers and assistants need to be trained in maybe 3-4 different methods and then they could decide which one would be most suitable for each individual child.

It must be appreciated how different children with autism are from each other and no one recipe will work for all children simply because they have a diagnosis of autism /Asperger's.

6.3.4 A report of the U.S. Surgeon General states:
(www.surgeongeneral.gov/library/mentalhealth/chapter3/sec6.html)

Because autism is a severe, chronic developmental disorder, which results in significant lifelong disability, the goal of treatment is to promote the child's social and language development and minimize behaviors that interfere with the child's functioning and learning. Intensive, sustained

special education programs and behavior therapy early in life can increase the ability of the child with autism to acquire language and ability to learn...

Thirty years of research demonstrated the efficacy of applied behavioral methods in reducing inappropriate behavior and in increasing communication, learning, and appropriate social behavior. A well-designed study of a psychosocial intervention was carried out by Lovaas and colleagues (Lovaas, 1987; McEachin et al, 1993). Nineteen children with autism were treated intensively with behaviour therapy for 2 years and compared with two control groups. Follow-up of the experimental group in first grade, in late childhood, and in adolescence found that nearly half the experimental group but almost none of the children in the matched control group were able to participate in regular schooling. Up to this point, a number of other research groups have provided at least a partial replication of the Lovaas model (see Rogers, 1988).

Several uncontrolled studies of comprehensive center-based programs have been conducted, focusing on language development and other developmental skills. A comprehensive model, Treatment and Education of Autistic and Related Communication Handicapped Children (TEACCH), demonstrated short-term gains for preschoolers with autism who received daily TEACCH home-teaching sessions, compared with a matched control group (Ozonoff & Cathcart, 1998). (pp. 7-8)

6.3.5 Common Elements

Following their close review of early intervention model programmes, Dawson and Osterling (1997) concluded that there were the following 'common' elements across successful approaches:

1. Curriculum content, emphasizing five basic skills-
 - a) ability to attend to elements of the environment that are essential to learning and to comply with teaching demands
 - b) ability to imitate others, verbal and motor
 - c) ability to comprehend and use language
 - d) ability to play appropriately with toys
 - e) ability to socially interact with others, especially peers.
2. Highly supportive teaching environments and generalisation strategies.
3. Need for predictability and routine.
4. A functional approach to behavioural problems.
5. Planning for the transition out of preschool, by teaching the following requisite skills-

- a) complying with requests from adults
 - b) turn taking
 - c) listening to directions from near and far
 - d) sitting quietly during activities
 - e) volunteering
 - f) raising hand to gain attention
 - g) walking in line
 - h) using toilets in the classroom (vs in the hallway)
 - i) tidying up after toy play
 - j) communicating basic needs.
6. Family involvement, i.e. the recognition that parents are critical to their child's success, and the provision of time and training to them.

6.4 The Task Force supports the principles of good knowledge of ASDs and good, evidenced based teaching practices which respect the concept that a particular approach may be best or indicated for a specified time period or activity, but should not be followed beyond the point at which it is needed. If teachers are to implement a particular approach, training and ongoing supervision should be provided. Generally, it is important that teachers and others involved in the education of students with ASDs, have a very good understanding of the nature of the students' particular autistic spectrum disorder, can apply shaping, fading and generalisation techniques, and recognise that individually designed modifications to methods being followed will be necessary to facilitate students, particularly the more able students (AS/HFA), to reach their true potential and highest level of independence. The Task Force supports the reflective practitioner model of teaching, where the system has the capacity to be flexible, and teachers think/plan and then react from a diverse knowledge base in meeting the objectives on the student's Individual Educational Plan, in conjunction with members of the intervention team.

6.5 Communication approaches.

More recently there has been an increased emphasis on addressing the communication deficits associated with ASDs. Numerous approaches have been adapted for use, particularly with those children with little or no spoken language. These are not a substitute for individualised direction and/or input from a speech and language therapist, but appear promising. Examples of these are:

- Hanen Programme (adapted for children with autism): where parents and staff are videotaped interacting with the child and these are conjointly analysed to identify communicative intent and teach the adults to respond to the child's lead, and to 'observe, wait and listen' to allow the child the opportunity to communicate.

- Picture Exchange Communication System (PECS): where students are taught to give someone a picture in exchange for what they want, thus helping the child to understand the function of communication. It encourages the child to *initiate* spontaneous communication. It was designed for young and preverbal children and follows eight defined stages.

6.6 Approaches for students with AS/HFA

6.6.1

Although many students with ASDs will require specialist ASD specific educational approaches, it is important, also, to recognise that the needs of students with AS/HFA in mainstream inclusive settings will need to be addressed through adaptations/additions to the curriculum, and by access to the ancillary therapies, supports and activities that are commonly recommended to ameliorate the effects of the triad of impairments common to all those with ASDs. Extra curricular supports, which aid social inclusion, community integration, independence and the overall well being of such students, therefore will need to be devised and provided on the basis of individually identified needs for those enrolled in mainstream inclusive settings.

The diagnostic label should never be assumed to convey a precise or preconceived set of behaviours and needs. Its main function is to convey an overall sense of the pattern of difficulties present. Professionals should never start a discussion of the child's needs by evoking the label. Rather, they should provide a detailed description of evaluation findings that resulted in the diagnosis of Asperger's Syndrome . A discussion of any inconsistency with the diagnosis, as well as of the clinician's level of confidence in assigning that diagnosis, should also be provided. (Klin et al, 1996)

The Report of the Working Group on Asperger's Syndrome (SWAHB, 2001) emphasises the critical need for understanding of the social skills deficit and communication problems which are core impairments of AS/HFA. The report stresses the need for clarity regarding the interventions required to redress the balance and states that:

The social impact of these difficulties (social, pragmatic language & communication skills) is significant and results in an inability to relate to others in a conversational manner. Language delays may be identified as one of the causes for poor relationships, bullying, victimisation and loneliness and may result in referral to the Speech and Language Therapist. What needs to be established is the underlying mechanism causing these ongoing difficulties. Any degree of impairment in socialisation however subtle has a devastating effect on the life of an

individual and the need for specific and sustained support is imperative (p 19).

- 6.6.2** As the needs of individual children and young persons with ASDs may fluctuate and change over time, it is important to acknowledge that some students may need to move between specialist and mainstream provision at different times throughout their education. However, some students with ASDs, and particularly some of those with AS/HFA, (depending on the severity of the autistic traits) will have the ability to follow the primary or secondary curriculum if appropriate supports are in place in the mainstream setting.

All persons diagnosed with AS/HFA should have access as required to speech and language therapy, occupational therapy and the support of a clinical/educational psychologist, to assist them to reach a point where they can fully avail of the benefits of education. All therapeutic/educational intervention, early intervention initiatives, pre-school services and support services for people with AS/HFA should be equally accessible regardless of whether education placements are in home based, specialised or mainstream settings. Twachtmann-Cullen (O.A.S.I.S.) identifies the following as key areas that need to be addressed in educating students with Asperger's Syndrome:

In order to create an hospitable environment for children with Asperger's Syndrome in a world that is often inhospitable to their needs, it is vital that teachers and other caregivers employ direct teaching strategies to address the following specific areas:

- *Perspective-taking*
- *Socio-communicative understanding and expression*
- *Reading/language comprehension*
- *Executive dysfunction (i.e., problems in organisational skills/planning)*
- *Problem solving*

Together, these target areas constitute a kind of life skills curriculum for the more able student. Their inclusion in the student's IEP can help to ensure that each of these important skill areas gets the attention it deserves. After all, life skills are far too important to be left to chance!

(See appendix 8 for full text of Twachtmann-Cullen paper.)

- 6.6.3** The development of social, communication and pragmatic language skills of those with AS/HFA may be addressed by a variety of strategies which include:

- a) Speech and language therapy: as persons with AS/HFA have literal interpretation because of difficulties with pragmatic and conceptual language and difficulty with metaphors, sarcasm and humour, they experience serious difficulties understanding the intentions and views of others and it is important that school staff be aware of these characteristics. The vital input of speech and language

therapists in the development of ASD children is fully recognised by the Task Force. Many of those with AS/HFA will need some individual speech and language therapy in addition to communication training. The Hanen Language Programme is also considered to be beneficial for some children with AS/HFA.

- b) Carol Gray's 'Social Stories': this technique seeks to teach social skills and aid the child's social comprehension by using specific social situations in the child's actual experience by the creation of short stories. The stories are based on guidelines that include directive, descriptive, perspective and control sentence types, which describe the particular social situation in terms of relevant social cues, anticipated actions and information regarding the reasons for what is occurring. The perspective, level of social understanding and underlying reasons for the child's unusual behaviour is revealed and gradually the child learns codes of social conduct by intellectual analysis rather than by intuition. This promotes improved opportunities for successful social communication and allows others e.g. teachers, parents etc. to accurately interpret the child's intentions in a given social situation.
- c) Social Scripting: a set of behaviours are prescribed and learned for the student to follow in designated settings or situations.
- d) Social Autopsies: a student is brought through a recent event (preferably videotaped) and assisted to explain their perception of the situation, and to learn the actual critical components of the situation and how and why their behaviour was inappropriate. They then have an understanding from which to 'script'/prescribe from themselves, more appropriate responses for similar situations.
- e) Social Understanding/Skills groups: Small structured groups (maximum of six) facilitated by speech and language therapists and/or psychologists or others with appropriate knowledge of AS/HFA to provide an opportunity for older children, adolescents and adults with AS/HFA to gain an understanding of their difficulties and develop strategies to enhance peer communication skills and social competence, particularly with peers. Discussion, self-disclosure, and the use of videotapes of participant's interactions, role-plays, and popular TV sitcoms (e.g. Mr Bean, Third Rock from the Sun etc.) are considered to be a critical part of the therapeutic process. Awareness of conversation rules, appropriate 'reading' of social cues, topic shifting/management, general pragmatic language skills, anger management, friendship skills and independent living skills are addressed in a safe and supportive environment which encourages the views and active participation of each member.

Aarons and Gittens (1998) constructed a Social Skills Communication Training programme for more able verbal children and adults with AS/HFA. The programme aims to teach social communication skills with reference to the triad of impairments. They stress that any social skills programme must be

developmentally based and include parents, teachers, and therapists in a group setting.

- f) Buddy systems, Mentoring and Advocates: students with an ASD do not readily integrate and develop friendships with peers despite an intense desire on the part of many to do so. Success has been reported using a strategy whereby an assigned peer agrees to act as a 'buddy' by watching out for and befriending the person with Asperger's Syndrome in some less structured social situations e.g. lunch time, break time, going to and from school etc. Such buddies might also assist in the development of leisure skills, opportunities to interact with peers etc. Teachers can often act in a mentoring capacity within the school, and college students are sometimes willing to 'mentor' or help adolescents by accompanying them on a community outing each week (e.g. coffee shops, restaurants, the cinema, or the gym). This mentoring approach is often effective in terms of imparting social skills and complements instruction from parents and teachers.
- g) Counselling: individual/group counselling will be necessary for many adolescents with AS/HFA to assist them to come to terms with the implications of their disorder, to address emotional, behavioural and educational issues which may arise. Increased recognition of the over representation of psychological difficulties in people with Asperger's Syndrome has led to renewed interest in developing appropriate forms of clinical work for this group. Cognitive behaviour therapy, with modifications to accommodate the cognitive profile of people with Asperger's Syndrome, may prove beneficial. Social skills training also can be incorporated into counselling. Siblings and parents of this group of students are also often need of such emotional and practical support.
- h) Occupational Therapy: to address underlying motor, vestibular, and skills deficits, which are often deficient relative to overall IQ and as such may affect the individual's acquisition of adaptive skills and academic performance (e.g. writing, drawing). The role of the occupational therapist is invaluable in dealing with the difficulties of students with AS/HFA. The primary aim of such therapy is to develop strategies to increase independent functioning, to foster and enhance abilities which improve quality of life. Where organisational and other learning skills are identified as needs, a prescriptive plan aimed at availing of assistive devices (e.g. electronic organisers and computers) to assist in achieving academic goals, self reliance and independence may be developed in conjunction with the occupational therapist.
- i) Information and Communication Technology (ICT): There are many advantages, not least the natural affinity with computers that many children with an ASD often exhibit. Predictability, user control, and the fact that their use does not require spoken language are also positive features. Software which provides a framework for organising and structuring the student's work, and tools for grammatically correct writing empower those with grapho-motor deficits and reduce the frustration experienced by students with such difficulties. The use of

computers promotes self initiative and self reliance in the context of developing special interests. It also offer those with AS/HFA increased opportunities for independence and the skills to access information, and communicate electronically in a non-threatening and anxiety free environment. They can be used to foster communication, social interaction (e.g. turn taking games), and pre-academic and academic skills and concepts and accommodate the visual learning styles of many children with an ASD. Many persons with AS/HFA have developed successful careers in the computer industry. On the negative side, computer activities risk becoming an obsession with many children with an ASD. Internet access should be monitored carefully with school-aged children in recognition of the vast amounts of uncensored information available. It also has the potential to be used as a substitute for direct instruction. Therefore, computer use must be given serious attention in how and when it is to be made available.

The Department of Education and Science makes available an additional computer grant to schools which have a special class. Schools may also make application for individual students, including those in mainstream who have special needs. This initiative needs to be expanded to insure that *every* child with an ASD has daily access to a computer to facilitate their educational and social progress. Parents are advised that some companies will provide both hardware and software at a discount to parents of children with special needs. Parents might also ask if they can take the software on trial and return it if it proves unsuitable to their child (see Appendix 9 for sources).

Gaining Face, a facial recognition software computer programme, is designed to help people with AS/HFA to learn to recognise and interpret facial expressions correctly. Further information on this programme is available at www.udel.edu/bkirby/asperger/

6.6.4 Recommended guidelines for AS/HFA

The following positive program specifications are based on the work of Ami Klin, Ph.D., and Fred R. Volkmar, M.D. (2000) of the Yale University Child Study Centre. They are considered by the Task Force to be a valuable resource when decisions are being made on appropriate placements and programs for individuals with AS/HFA. For this reason the relevant section of the publication is quoted in full, with kind permission of the authors, in appendix 10. It is acknowledged, of course, that the specifications are not applicable to every individual with AS/HFA in every part of the country but they do have particular relevance for first and second level:

6.6.4.1 General Intervention Strategies

- Relatively small setting with ample opportunity for individual attention, individualised approach, and small work groups;

- The availability of a communication specialist with a special interest in the pragmatics of language and social skills training;
- Opportunities for social interaction and facilitation of social relationships in fairly structured and supervised activities;
- A concern for the acquisition of real-life skills in addition to the academic goals;
- A willingness to adapt the curriculum content and requirements;
- The availability of a sensitive counsellor who can focus on the individual's emotional well being, and who could serve as a co-ordinator of services.

6.6.4.2 Specific interventions

- Skills, concepts, appropriate procedures should be taught in an explicit and rote fashion;
- Specific problem-solving strategies should be taught for handling the requirements of frequently occurring troublesome situations;
- Social awareness should be cultivated, focusing on the relevant aspects of given situations, and pointing out the irrelevancies contained therein;
- Generalisation of learned strategies and social concepts should be taught, from the therapeutic setting to everyday life;
- To enhance the individual's ability to compensate for typical difficulties processing visual sequences, by making use of equally typical verbal strengths;
- The ability to interpret visual information simultaneously with auditory information should be strengthened;
- Self-evaluation should be encouraged;
- Adaptive skills intended to increase the individual's self-sufficiency should be taught explicitly;
- The individual with Asperger's Syndrome should be instructed on how to identify a novel situation and to resort to a pre-planned, well rehearsed list of steps to be taken;
- The link between specific frustrating or anxiety-provoking experiences and negative feelings should be taught to the individual with AS/HFA in a concrete, cause-effect fashion;
- Additional teaching guidelines should be derived from the individual's neuro-psychological profile of assets and deficits.

6.6.4.3 General Strategies for Communication Intervention and Social Skills

Explicit verbal instructions on how to interpret other people's social behaviour should be taught and exercised in a rote fashion. The meaning of eye contact, gaze, various inflections as well as tone of voice, facial and hand gestures, non-literal communications such as humour, figurative

language, irony, sarcasm and metaphor, should all be taught in a fashion not unlike the teaching of a foreign language:

- The individual with Asperger's Syndrome should be taught to monitor his/her own speech style;
- The effort to develop the individual's skills with peers in terms of managing social situations should be a priority;
- The individual with AS/HFA should be helped to recognise and use a range of different means to interact, mediate, negotiate, persuade, discuss, and disagree through verbal means.

6.6.4.4 Academic Curriculum

- The curriculum content should be decided based on long-term goals, so that the utility of each item is evaluated in terms of its long-term benefits for the individual's socialisation skills, vocational potential, and quality of life;
- Emphasis should be placed on skills that correspond to relative strengths and special interest for the individual as well as skills that may be viewed as central for the person's future vocational life;
- Specific projects can be set as part of the person's marking/grading criteria, and specific mentorships (topic-related) can be established with staff members or individuals in the community;
- It is often useful to emphasise the utilisation of computer resources, with a view to: (a) compensate for typical difficulties in grapho-motor skills; (b) to foster motivation in self-taught strategies of learning, including the use of "on-line" resources; and (c) to establish contact via electronic mail with other people who share some interests.

(Klin & Volkmar, 2000)

6.6.4.5 Music Therapy & Physical Education

- a) Music Therapy: this is an enjoyable non-ASD specific therapy, which encourages attention, imitation, and communicative interactions. It is based on the idea that music may open up channels of communication and thus offer increased opportunities for the expression of emotion. Music therapy is more beneficial in a relationship fostered between the child and key worker, teacher or parent, rather than a therapist who is otherwise uninvolved in the child's life, although training is required.
- b) Musical Interaction Therapy: This ASD specific therapy prioritises communication skills and is used both in schools and in clinical practice. It operates by supporting interactions between the child and a parent/key worker while a musician plays an instrument, which facilitates the communication and interaction. Singing is also used to increase interest and understanding in

routine activities and learning, to capitalise on the child's natural tendencies towards sensory rhythm, etc.

- c) Some students with AS/HFA, particularly those in second/third level mainstream education do not participate in any physical activities. Clumsiness, (motor deficits), lax-joint difficulties, a dislike of physical team sports, fear of peer ridicule, and awareness of their unpopular status among peers as team members, can preclude them from taking part in all physical activities. The solitary and marginalised lifestyles common to this group also tend to prevent them from accessing opportunities to participate in such activities. As we are aware of the importance of physical exercise in maintaining good physical and mental health, the sedentary lifestyles of this group are a genuine cause for concern, and merit serious attention. The Departments of Education and Health should encourage, support and provide funding for young people with AS/HFA to participate in physical exercise and activities, whether by joining local gyms and Health Centres or by the pursuit of other activities in an effort to maintain/improve their physical and mental health and to further extend positive social opportunities.

In technical terms there may be a lack of upper and lower limb co-ordination (Hallet et al, 1993). This feature can be quite conspicuous and other children may tease the child, leading to a reluctance to participate in running sports and physical education at school (Attwood,1998, p 104).

Catching and throwing accuracy appears to be particularly affected (Tantem, 1991). Clinical observation also suggests the child has poor co-ordination in their ability to kick a ball. One of the consequences of not being good at ball games is the exclusion of the child from some of the most popular social games in the playground. They may avoid such activities because they know they lack competence, or are deliberately excluded because they are a liability to the team (Attwood,1998, p 105).

6.7 Conclusions of the Task Force with regard to teaching approaches

6.7.1

There are other empirically supported educational approaches. Such approaches use marked routines or music, e.g., to establish early social interaction and communication and/or use visual structure to help the student make sense of instructions and begin to learn how to learn. Some utilise the student's intact resources for learning by developing compensatory and remedial cognitive skills and many involve parents and key workers in establishing ways of working with, and assisting, the individual throughout the day. There are also encouraging results from programmes that use peers to help tutor the student (Strain et al, 1996). Parental permission and the agreement of the person with the ASD, where applicable, should always be sought before embarking on such initiatives. There

are reviews of all of these approaches, including those based on Applied Behaviour Analysis and TEACCH included in Dawson and Osterling, 1997; Harris & Handleman, 1994; Howlin, 1999; Jordan et al., 1998; Rogers, 1996, and Heflin and Simpson, 1998. All support the contention that early systematic intervention makes a significant difference to the development of students with ASDs.

Swimming and horseback riding have traditionally been popular in special needs programmes and some students with Autistic Disorder and PDD-NOS appear to enjoy them. Team sports are generally avoided due to the nature of this disorder, however sports such as golf, bowling, Karate, hill walking, etc. can be educationally and socially beneficial to those with Autistic Disorder.

Other intervention strategies recommended for use with those with an ASD have been less rigorous in evaluating their success. Some are narrow in focus, e.g. only addressing communication skills, but are presenting good outcome data for their specific purpose (e.g. PECS) and can be incorporated to contribute to a more holistic and balanced approach. The Task Force believes that evidenced based approaches should be most seriously considered when choosing intervention options. Unvalidated or poorly researched methods should be avoided or incorporated only where an evaluative component is included.

There is a paucity of empirically validated AS/HFA specific interventions, although research in this area is improving. All intervention should be critically evaluated with a view to the wider dissemination of information regarding appropriate educational strategies for persons with AS/HFA as well as classic autism. At present, there is no definitive evidence that supports one approach as being better than others for all children with ASDs, or supports a single approach for all aspects of development; nor is there any evidence by which children could be matched to particular approaches. In such a situation, informed parental wishes should be an essential factor in determining the programme offered. Parental training programmes (such as 'EarlyBird' from the National Autistic Society, UK) can help parents of young children develop their understanding and skill in working with their own child and guide them in making suitable choices to meet their child's and their own needs.

6.7.2

In reality, there are very, very few programmes that actually follow a pure delivery of one approach to the exclusion of all others. This reflects the development of various models over the years and the recognition that many have at least something positive to offer to the education of children with an ASD.

To date, ABA and TEACCH approaches have the most documented support standing alone for children with ASDs, with ABA following an experimental research design, and TEACCH primarily, but not exclusively, presenting

programme evaluation results. Other programmes combine ‘curriculum’ and ‘approaches’, and are typically presented at professional conferences. They are increasingly publishing their positive results, however, and these should be regularly reviewed and considered. As noted throughout this Chapter and others, children with AS/HFA present with their own unique learning needs, and the setting in which adapted/modified specialist programmes and approaches for these students are delivered, therefore, will differ from those designed for the less able, and also must address the issues included herein.

Additional programmes specific to early intervention are included in Chapter 7 of this report.

6.8 METHOD OF DELIVERY

6.8.1

Special educational and clinical services may be provided in conventional and creative ways across the range of settings. The availability of staff should not, but may unfortunately, limit the choices in a geographical area, at least for the time being, so various models of service delivery need to be developed. Examples are 1:1 and group work, discipline specific training of those in routine contact with the child, consulting by phone and in person, video reviews, etc. The educational/intervention plan should always specify the ideal circumstances under which the child’s goals and objectives would best be reached, whether or not the stated resources are available. When they are not available, they should be requested from the relevant Government Department. The educational planning team should then specify how they will proceed in the interim.

6.8.2

The recommended range of educational placement options are offered under each of the age-specific subsequent chapters. In all cases, the child’s diagnosis and level of intellectual, social and academic functioning must be considered to insure compatibility within the peer group and homogeneity of curriculum and teaching approach. The Task Force have identified the need, therefore to provide two differentiated models of provision for ASDs. One model for those with AS/HFA and average levels of intellectual ability, and another for those with ASDs and additional intellectual disabilities. Some are new concepts for Ireland, while others are in need of refinement. One, the home tuition scheme, is in need of modification as the purpose of home education of children with an ASD differs from that of those who are ill, for whom the scheme was originally devised. Children with an ASD may require, or parents prefer, home education for a variety of reasons, e.g. no suitable class offered or available, behaviour requires a very gradual transition into the group environment, child is school-avoidant due to bullying or lack of provision of sufficient support particularly in the mainstream

setting, child is on a highly restrictive diet, or the type of intervention agreed does not exist in the child's locale. Such students require full-time education with qualified teachers/tutors on pay and benefit scales equal to those working within schools. Parents of students with ASDs experience enormous difficulties locating teachers willing to participate in the home tuition scheme. This is placing an extra burden on such parents and families. The Task Force recommends that the Department of Education and Science, through the inspectorate or the Special Needs Organisers (or relevant department official), should bear the responsibility of locating, training and employing teachers to support those availing of this scheme. Parent and teacher training, systemic supports, equipment and supplies, and clinical services must be available to those on the home tuition scheme as well.

6.8.3

Holiday schemes (differentiated, for example, into AS/HFA specific *and* autistic disorder specific) must also be developed. The risk of regression during long summer holidays is a serious concern for all students with ASDs. Students in mainstream classes will not benefit from the extended year available to those in specialist settings and therefore are in particular need of such schemes. The introduction of summer projects, which would include day and residential educational programmes, social skills groups/social clubs, hobby and special interest clubs, camps and holiday schemes, should be provided to cater for the social and educational needs of this group. These schemes should be implemented with due sensitivity to the awareness and difficulties of intellectually able students with AS/HFA and involve unpaid 'buddies' as well as paid support workers, and should include community activities. After-school clubs should also be provided during the school terms.

6.8.4

It is important to note that where a para-professional is associated with the child, his/her interaction with the child must be planned, directed and monitored by professionals. This is to insure that a classroom assistant or home support worker is not overly responsible for a child who, by the nature of their condition, needs the most expert knowledge at their disposal.

The observation that students with AS/HFA are often assessed as being below expected levels of academic proficiency in spite of average intellectual ability on the basis of assessment by a psychologist, needs to be researched and results translated into effective intervention.

6.8.5

The assumptions about teaching and learning cited in *Adapting Curriculum & Instruction in Inclusive Classrooms* (2000) are relevant to this section:

- *Students differ in their learning preferences and need multiple and varied avenues to learning.*
- *All students can learn what is important for them to learn.*
- *Teachers make the difference.*
- *Instruction must be meaningful.*
- *Curriculum, assessment and instruction are inseparable.*
- *Diversity should be valued and respected.*

A submission which reflected a number of those received stated:

Some approaches are favoured to the exclusion of others by some professionals and we believe that this may not be an equitable approach at service level to take as any one child may need different approaches at different stages in their development. We therefore recommend the following:

-That each region offer a range or menu of educational options based on the comprehensive, individualised assessment of need;

-That all methods are monitored on an ongoing basis through systematic, empirical research.

An integrated approach is supported also by many of the studies cited in this Report. It should be noted that distinct teaching methodologies, e.g. ABA and TEACCH, will acknowledge that they also include a variety of strategies during the course of the school/home programming day, while retaining the integrity of their approach.

The Task Force concludes that the quality of the intervention will be enhanced if it is based on a thorough assessment of the student's learning capacities, including a profile of the impact on the child's learning of his/her ASD, and indeed on the needs of the student's family. This may occur over a period of time, and will be subject to periodic review, at least annually. The types of intervention employed will depend on multiple other factors, e.g. the skills, knowledge and theoretical beliefs of the teaching and clinical staff and parents; the availability of mainstreaming opportunities, etc. Based on submissions received and review of professional documents, the Task Force concludes that provision should reflect individual student needs, parents' access to choice, with a range of approaches and settings considered and then clearly specified in each child's Individual Educational Plan, taking into consideration the outcome literature. This will require staff's access to material and training in currently popular methods while remaining abreast of new interventions. This will meet the student's specialised needs as well as those related to normal childhood/adolescent development and experiences.

6.8.6

The overall conclusion from this section indicates the need for the Department of Education and Science to fulfil the commitment made in the SERC Report (1993) to set up curriculum development projects for pupils with disabilities and special educational needs, in association with appropriate schools, colleges, institutes and organisations. The Task Force findings indicate that approaches and strategies employed in the provision of education for children with the various ASDs should promote social skills, communication, flexibility in thinking and behaviour, and should allow the child or the adult to manage behaviour and emotions appropriately, and with independence. In these circumstances, education is for life and should influence life and leisure skills and experiences. The Task Force recommends that the general and specific issues relating to ASDs should be investigated further through research with a view to creating a set of criteria which can be applied at the point of diagnosis, and educational assessment to match a child with an ASD to a given approach, or to an eclectic use of approaches. It is apparent from the review of research that the treatment of children with ASDs should be grounded in research and research projects should receive a high priority by the Departments of Education and Science and Health and Children. Accordingly, the Task Force recommends that the Department of Education should tender additional, Irish based research in the areas of eclectic, and single, mainstream and specialist approach programmes in order to inform the educational system, particularly parents, of the most appropriate method of teaching children with ASDs.

6.9 Curriculum

There is a need for the proposed Special Needs Organisers, as a matter of priority, to initiate the fulfilment of recommendation in the Report of the Special Education Review Committee (1993) with regard to ASDs:

The National Council for Curriculum and Assessment should set up curriculum development projects for pupils with disabilities and special educational needs, in association with appropriate schools, colleges, institutes and organisations.

A set of criteria should be referenced when evaluating any approach, and controlled, comparison studies are recommended.

6.10 Inclusion

6.10.1

Inclusion in schools refers to the philosophy that children with specialised needs should receive their education and support services within the least restrictive and most normalised setting. Inclusion focuses on the school making the necessary

accommodations to include and integrate those with special needs in the school's mainstream classrooms and activities, so that they might participate in all aspects of school life. Inclusion ideally promotes the same opportunity for education, rights and responsibilities for all, in a barrier-free system, where parents, pupils and school staff collaborate and reflect the diverse nature of persons in the community. This follows a Social Model where the barriers to equality are placed on the environment 'versus' the individual (the Medical/Disability/Integration Model). There are a variety of issues that need to be addressed in order to make the educational system truly inclusive. It must be accepted that having any student with special educational needs is a responsibility for everyone in the school. This is and will be, an educational process for all involved. A change in attitudes, understanding and knowledge is needed to ensure that rather than seeing special education as taking place in a separate place, special education is brought into mainstream classrooms and environs.

Much has been written about the placement of children with special educational needs, including those with ASDs, in mainstream schools. The trend of international opinion and research indicates that children with ASDs can make good, and often better progress alongside their peers with no adverse effects on the performance of their mainstream peers. The present spirit of the law is in favour of initial consideration of a mainstream placement for all children. Based on outcome studies (Psychological Society of Ireland document, 2000), the Task Force is in strong support of Inclusive Education for those with an ASD. Strategies and initiatives to markedly improve access to appropriate education in the least restrictive setting, with daily involvement by students with an ASD at all levels of intellectual and adaptive functioning, with a typically developing peer group, must be designed and implemented in Ireland.

6.10.2 Inclusion in Mainstream Education

Four Task Force submissions, one from a group representing approximately 400 families, pointed to the difficulty of arranging placement for students with AS/HFA in mainstream primary and post-primary schools. They experienced that school authorities were reluctant to consider a child for admission when ASDs were mentioned. The Task Force is acutely aware of the struggle which many parents have to face when trying to have their child educated in a mainstream school and believe that parents should not have to face the issue of educational placement without support. The formal statement of need introduced in this report should provide legislative strength for the parents to access the placement indicated in the statement.

One contributor framed their experience in terms of the need for a policy on integration:

Any integration policy is at the discretion of the class teacher. In some schools, the perception of the autistic child is diminished to begin with, i.e. they are badly behaved or spoilt and therefore integration is diminished. The Department of Education [and Science] needs to be strong and united on its integration policy.

The principle of inclusion is prominent amongst parents and special needs professionals, together with the principle of making provision in the least restrictive environment. The case for unequivocal commitment to inclusion is proposed in another submission:

Inclusive education should be firmly promoted as a realistic and realisable goal and not placed in parenthesis for those who may attain within the education system 'with support.' A commitment to provide whatever support is needed should be the rule and not the exception.

'Inclusive Education' and 'mainstreaming' promote the ideal of equality of opportunity, acceptance, belonging and social inclusion by providing choice and quality of support by maximising opportunities for participation and ensuring that positive opportunities for learning take place; however, evidence to the Task Force (e.g. submissions, research and the literature on ASDs) suggests that inclusion does not occur simply by placing students with ASDs in mainstream environments, even with resource teachers and classroom assistants. There is currently little evidence to suggest that inclusive goals are being met (National Autistic Society UK, 2000). Inclusion will always require informed, sensitive, age appropriate and collaborative planning and monitoring as multiple impairments, which may sometimes be subtle in presentation, nevertheless, impact on all areas of functioning and have severe consequences.

The Task Force considers the legal obligation on all schools to submit a Whole School Plan which includes a description of how the school plans to include students with special needs in the mainstream, as an important feature of Department policy. The Task Force suggest that this provision should be binding on all education providers and monitored by the Inspectorate. For those programmes that are not governed by the Department of Education and Science, the contracting authority should require them to submit an Inclusion plan, which should then be monitored by the contracting authority, e.g. local Health Board. In all cases, interventions should be reviewed against the goals set for each child.

6.10.3 Inclusive Education for AS/HFA Students

The importance of education for the development of the individual's potential cannot be overestimated and keeping the AS/HFA child at school for as long as possible should be the main focus of professional interventions (SWAHB, 2001, p vi).

Successful inclusion for students with AS/HFA in mainstream inclusive classes is dependant on the provision of additional support and accommodation to overcome the disadvantages of core social and communication impairments. The enrolment of students with AS/HFA in mainstream classes does not negate the need for the provision of ancillary supports and intervention to overcome the impairments of their condition as diagnosis is determined on the basis of the existence of a triad of impairments common to all autistic spectrum disorders. Children and adolescents with AS/HFA need to be taught, cognitively, the basic life skills that are normally acquired intuitively. Difficulties regarding the ability to transfer learning experiences and poor organisational skills imply that a holistic approach based on individually identified needs is warranted.

Parents report that children with AS/HFA, although noticeably different, appear to be happy and reasonably content in the early childhood years. Parents also routinely report that peer rejection/isolation increases throughout childhood and causes such distress that by early adolescence, many of these children become extremely disillusioned and their motivation to learn may drop significantly. Social exclusion and, in turn, isolation are potentially damaging and common problems for many children with AS/HFA of all ages. All persons diagnosed with AS/HFA should have access to age-appropriate social, communication and life skills training programmes across the range of educational settings. Schools with students who have AS/HFA will need to become aware of the following issues:

- the vulnerability of children with AS/HFA;
- recognition that labels can isolate and stigmatise and that children have a right to retain confidentiality among peers regarding their diagnostic status;
- the promotion of social inclusion in all aspects of school activities;
- awareness that bullying is an enormous problem and one that rarely receives the level of consideration that its seriousness actually merits. Formal guidelines and strong anti-bullying programmes are urgently needed. Individually identified, written strategies to overcome bullying, peer rejection and social exclusion should also be identified in collaboration with parents;
- discreetly ensuring that children with AS/HFA have suitable and willing partners for school tours, games and group activities will be essential to ensure the full participation of the group;
- the need for flexibility and awareness that the student may have difficulties that are not readily apparent to staff is essential in establishing a degree of understanding of the wider difficulties of the student with AS/HFA;

- the need for instructive and protective strategies to overcome difficulties which commonly arise during unstructured time also need to be identified and implemented in a discreet manner;
- an awareness that structure and routine accommodate the child with AS/HFA's need for security and is critical in order to establish an atmosphere where learning can take place. Preparation and clear explanations will be needed if change to the normal routine is to occur;
- regular communication should be established between parents and health and education professionals so that appropriate support can be maintained;
- to implement measures to promote acceptance of students with AS/HFA, i.e. encouraging those who may excel in a particular subject to help other mainstream students in that subject, thus raising the status and self esteem of the student.

Inclusion will only work if the focus of education addresses life skills and quality of life issues in conjunction with academic requirements as core components of the curriculum. There is a shortage of information regarding mainstream classroom strategies which accommodate the learning styles of students with AS/HFA. There is also a need to ensure that the ancillary supports required by students with the triad of impairments are available across the range of settings.

6.10.3.2 Although the majority of students with AS/HFA are in mainstream classes and some possess the undoubted potential to excel academically, (particularly in their areas of special interest) if appropriate levels of support are provided, evidence to the Task Force suggests that marginalisation, isolation peer rejection and social exclusion are difficulties which pose a continuing problem for those students with AS/HFA attending mainstream schools. Yet, this aspect of mainstreaming has received little attention to date. Bullying is a serious problem that can dramatically affect the ability of students to progress academically and socially. Although there are no statistics available relating to the extent of bullying which occurs in the ASD population in mainstream schools in Ireland, a nationwide study in Irish schools (O'Moore et al, 1997) reveals that bullying is widespread throughout primary and post primary schools in Ireland. A comprehensive intervention plan that involves all students, parents, and school staff is essential to ensure that all students can learn in a safe and non-threatening environment. Prevention of bullying should form part of teacher training, as it routinely prevents students with AS/HFA from attending school and remains a significant causal factor in the high drop out rate at second level. Positive policies on inclusion should include formal guidelines on bullying, 'anti-bullying' policies, and pro-active protection strategies combined with in-built opportunities to improve social understanding and foster positive social experiences with peers. The Department of Education and Science should identify a National policy/code of practice document which would outline key areas of concern and general

recommendations regarding the provision of support, protection and flexible education to meet the holistic needs of persons with AS/HFA in mainstream classes and schools. This policy should be circulated to all schools and parents of this group

A parent's submission states:

The absolute frustration of Asperger's Syndrome children in coping with the difficulties of second level schools combined with the lack of awareness by mainstream education of those difficulties is the major factor in the existing disastrous position.

Similarly, a psychiatrist states that:

Similarly, there is a huge gap between the primary and secondary provision and particularly those young people with Asperger's, who have the intellectual ability to cope with the secondary school curriculum but do very badly there because the system there does not suit them and they must run at very high stress levels. Individual schools try to do their best but they do not understand what is involved.

6.10.3.3 A study is needed to review the success of inclusive mainstream educational provision for students with AS/HFA and to identify strategies to support inclusive policies. There is a need for wide dissemination of accurate and detailed information on AS/HFA among education and health professionals. There is also a need to improve the retention rate at second level and to identify the adjustments that might prove beneficial in counteracting current low levels of academic attainment (despite high cognitive ability and academic potential) in students with AS/HFA.

There is a pressing need to clarify and rectify the subtle but serious educational implications that arise as a consequence of enrolment in mainstream 'versus' specialist education settings. Such issues include the current disparity in the provision of ancillary services between mainstream and special settings, the absence of identification, evaluation and monitoring systems in mainstream settings, and accurate information on educational attainment levels and outcome for individuals with AS/HFA who are outside the remit of designated autism and learning disability services in many regions. It is critical that dedicated structures are identified to ensure that inclusive policies are reflected in practice through the delivery of adequate provision in mainstream schools. If inclusive education is to prove a viable educational option for students with AS/HFA, much more is needed in terms of the scope of current provision in mainstream classes.

6.11 COMMON FEATURES ACROSS PROMINENT APPROACHES

The following is a list of common features which have been found to be useful and beneficial, across a variety of different approaches:

- Parents as partners
- Low student ratio; 1:1 best for 'new' learning (and as long as is beneficial)
- Observation of and learning from the child
- Pitching language and activities to child's current level
- Utilising a designated communication skills programme
- Individualisation within the classroom programme
- All significant adults using same approach, i.e. home and school
- Normal, developmental activities
- Emphasising routines (to facilitate understanding; caution re: errors of reinforcing nonfunctional routines or rigidity)
- Teaching functional skills
- Teaching of strategies
- Teaching of rules
- Teaching of concepts
- Incorporating strategies in instruction to increase student's independence
- Learning and using the precise behaviour-theory strategies of shaping, fading and positive reinforcement
- Using task analysis
- Organising and structuring space, materials, time, events, verbal inputs, etc.
- Addressing sensory differences
- Addressing spatial problems
- Evaluating frequently and revising/refining based on evaluation

- Constructing and using visual strategies
- Planning variations
- Planning for generalisation
- Planning for maintenance
- Using the child's strengths, interests and obsessions to facilitate new learning
- Repetition
- Expecting progress within specified timeframes
- Conducting functional analyses where necessary to understand any targeted behavioural barriers to learning and socialisation, and planning appropriate interventions.

6.11.2 Inclusion policies should include ready access to the local community for children and adults across the autistic spectrum. Teachers should insure that the student's education is not restricted to the classroom, but takes place 'in vivo'. As some persons with an ASD often have difficulty in supermarkets, restaurants, etc., behavioural education for this group must include routine community education sessions. Transportation for these must be made available on a weekly basis at the minimum, and should be arranged in a sensitive manner which will not 'stigmatise'. This aspect of arrangements is critical, particularly for those in mainstream schools and should be observed in recognition of the efforts of the more able students to maintain dignity and confidentiality regarding their condition.

6.11.3 The Learning Disabilities Group of the Psychological Society of Ireland recently prepared a document on Inclusion: *A Place to Learn*, (PSI, 2000), that should be referenced by schools and Department of Education and Science administrative staff for guidelines on understanding and facilitating inclusion. The section on *Research Literature* (p. 3), strongly supports inclusive education as being proven beneficial to children with a disability and their mainstream peers. Studies cited indicate that in general, special needs students do better academically and socially than students in segregated special educational programmes.

6.12 RECOMMENDATIONS

The Task Force recommends:

1. that the Department of Education and Science make available a range of approaches and therapies to meet the unique needs of each student with an ASD; that such provision includes, as appropriate, a choice/combination of home based, mainstream or specialist settings and the various core therapies of speech and language and occupational, and behavioural and physiotherapy when specified;
2. that a range of resources to meet the unique needs of each student with an ASD in all schools settings be provided by the Department of Education and Science; that this include appropriate adaptations to the curriculum, in-school/home counselling support, IT funding, youth club support, and holiday and after-school schemes;
3. that funding be made available for research into the effectiveness of various approaches and strategies used to support students with ASDs, including the specific curricular approaches to promote the academic potential and social and emotional progress of children with AS/HFA;
4. that the Department of Education and Science issue a national ASD policy directive which will emphasise the primacy of the principles of inclusion and the least restrictive environment, and which will require schools to include a statement of provision and curriculum access and support for persons with an ASD within the School Plan;
5. that the Department of Education and Science establish a committee, which will include parent representatives, to develop agreed guidelines and procedures for monitoring children's progress;
6. that schools enrolling students with ASDs ensure a 'whole school' ethos conducive to appropriately supporting the needs of these students;
7. that schools enrolling students with ASDs ensure that there is a written policy indicating the arrangements, including assessment and recording procedures, teaching approaches, support services, child safety provision, and staffing and material resources, to support successfully the needs of these students;
8. that schools enrolling students with ASDs actively promote inclusion for these students.
9. that the Department of Education and Science identify and circulate a formal standard policy and guidelines on anti-bullying; that anti bullying policies and proactive protection strategies are implemented, that bullying prevention, and how to respond to this issue, form part of teacher education, particularly for students with AS / HFA
10. that bullying prevention and how to respond to this issue, be part of teacher training, particularly for students with AS / HFA

- 11.* that schools enrolling students with ASDs actively promote inclusion for these students and that research be initiated to review the success of inclusive and special placements for students with ASDs.)
- 12.* that the Department of Education, through the inspectorate, SNOs or otherwise, take responsibility for the identification, training arrangements and employment of teachers to support students with AS/HFA who are availing of the Home Tuition scheme and also, for the employment, training and employment of the proposed Visiting Teachers for persons with ASDs.
- 13.* that community integration/ education and transport arrangements for adolescents with AS / HFA be age- and ability-appropriate, and arranged with due respect to the right of each individual to retain confidentiality regarding disability status among peers; that, where relevant and appropriate, grant support in lieu of special transport be provided in order to retain confidentiality;
- 14.* that community integration/ education and transport arrangements for adolescents with AS / HFA should be age and ability appropriate, and should be arranged with due respect to the right of each individual to retain confidentiality among peers regarding disability status.
- 15.* that individual/group counselling be provided for adolescents with AS / HFA to assist individuals to come to terms with the implications of the disorder and to address emotional, behavioural and educational issues which may arise.
- 16.* that the Departments of Education and Health should encourage, support and provide funding for young people with AS/HFA to join local Gyms and Health Centres, particularly during holidays, in an effort to maintain/improve community integration, and their physical and mental health through the provision of positive social opportunities
- 17.* that the Department of Education should provide a National policy / code of practice document which would outline key areas of concern and general recommendations regarding the provision of support, protection and flexible education to meet the holistic needs of persons with AS / HFA in mainstream classes and schools. This policy should be circulated to all schools and parents of this group.

CHAPTER 7

EARLY EDUCATION

7. INTRODUCTION

This Chapter will reference the current provision of early services to children with ASDs in the Republic of Ireland, the problems and deficits, review available knowledge in the area, and make recommendations for the immediate and long term future of early education for this population. Due to the information presented in this report, we consider the age range *from point of diagnosis* to and at times including, age five as pre-school, ‘versus’ the three – five years that is now generally accepted.

PROVISION TO DATE

- 7.1.1 The markedly inadequate state of early intervention for children with an ASD in Ireland was crystal clear in many of the submissions received by this Task Force. Considerable attention was paid to issues related to early diagnosis and intervention in forty-three of the submissions and was elaborated upon in twenty submissions. The following example was typical of the life stories shared:

J. was diagnosed as having an Autistic Spectrum Disorder at the age of 2 years and 3 months when our daughter was just 11 days old. In our innocence we thought that now we knew what the problem is we would get the help that we needed. How wrong we were. We spent the next 18 months being shunted around. We had nothing to cling to but some ‘words of advice’ which were imparted by one of the Professionals at one of the many appointments where we were told that there would be no services available for J. until he was at least 5 or 6 years old. So, that being the case, and considering that autism is incurable anyway, we should go home and concentrate on rearing our other two children. Imagine for a moment, if you will, being given this piece of ‘advice’ about your child, your only son, when what you so desperately needed was practical help and advice on how to address his many needs. Think of the frustration. We were frantic.

When early intervention is not accessible, which is often the case for those with an ASD, the knowledge of what can be achieved leads to terrible frustration for both parents and professionals. In their submission, one group of parents summed up this sense of frustration, in the comment that:

...all the experts say that early intensive intervention is so important and we watch helplessly as the years slip by.

7.1.2 A National policy on the provision of early services to children on the autistic spectrum is finally emerging. In 1993 the Special Education Review Committee recommended that:

The Departments of Education and Health must ensure that pre-school education is made available to all pre-school children with disabilities and/or special educational needs. Financial assistance towards the cost of privately-owned services should be provided to parents of such children.

The 1999 White Paper on Early Childhood Education, “*Ready to Learn*”, included autism in the government’s policy to expand pre-school education to children with disabilities. In October 2000 the current Minister of Education announced a national educational service for all children with autism. This included the intention to introduce a nationwide preschool education service for children with autism. This policy is laudable. It should be implemented with immediate effect. When the implementation mechanisms are in place to make this a reality, they must include the full range of Autistic Spectrum Disorders from time of diagnosis. The Task Force validate the Minister’s intended action and see this report as providing the background to securing the services promised in his statement.

7.1.3 To date in Ireland generally, the diagnosis of an ASD comes later than with other developmental disabilities, such as Down Syndrome, as described in Chapter 4 of this Report. This is particularly true for children with Asperger’s Syndrome and high functioning autism who are rarely diagnosed before attending primary school. Without a diagnosis, there is little chance of receiving the specialised intervention that would be most beneficial. Some children with autistic disorder are included in their local voluntary service providers funded by the Department of Health and Children, or Health Board Child and Family Centre’s early services programme. They may receive periodic home visits from team members and attend for 1:1 programming beginning with two hours per week, and working up to four half days per week with peers who also exhibit developmental difficulties. Nurses with specialist training in mental handicap are the primary service providers, and where available, a Psychologist, Speech and Language Therapist, Occupational Therapist, Social Worker and Consultant Child Psychiatrist will be on the child’s team. This is the exception, rather than the rule, however, as the majority of very young children received a minimalist service.

1. Traditionally children with an ASD who did or did not receive an early diagnosis, were accommodated in programmes for the intellectually disabled or emotionally disturbed. Up to very recently, the staff’s knowledge of, and experience with, autistic spectrum disorders was minimal or otherwise inadequate, and so they were not in a position to effectively address the communication and learning needs that are associated with ASDs.
. Additionally, the pre-school child with an ASD typically requires at least a 1:1 support to learn new skills and appropriate behaviours and may not integrate readily with the other children. Thirdly, there are waiting lists for

these services and consequently long delays before identified children are included in existing services. As these services are overly stretched, they have increasingly been less willing to either take in or continue to provide for those with an ASD diagnosis. For many other young children with an ASD, there simply is nowhere for them to go. Pre-schoolers with AS/HFA, if they are identified early, are typically inappropriately placed in programmes with more severely affected children. The scenario quoted under 7.1 is not unusual. There are many children with ASDs in Ireland who do not go to school until they are six years old due to a lack, or absence of, suitable programmes. Home support and supported home programmes, are also rarely available. Given the acknowledged benefits of specialised intervention for children with ASDs under the age of four across the spectrum, this leaves the majority of these children in a state of neglect and parents in a state of being extremely upset.

7.1.4 Murray (2000) found that seventy-five per cent of fifty-two parents surveyed reported the main problem following a diagnosis of an ASD for their child, was lack of information. Fifty-two per cent found no suitable pre-school available:

Overall, services at diagnosis were rated as poor by 65% of parents.
(p. 13)

1. Parents themselves have increasingly been the primary service providers for their very young children with an ASD. Many educate themselves around the nature of the disorder and methods of intervention, secure premises or modify their homes to accommodate a full-time home educational programme, pay for staff and hire therapists at their own expense, or place their child in settings abroad at their own expense, during their children's early years. They do this only because little or nothing else is offered by either the Health Board or Department of Education and Science, or because what is currently provided does not meet their children's special needs. However, the Department of Education and Science has recently agreed to absorb some of the costs associated with the private arrangements outlined above.
1. Many children with an ASD attend local playgroups or Montessori classrooms on a part time basis. These teachers and their staff are empathic to both the children and their parents and most go out of their way to accommodate the child's special needs. The children make progress in these settings, but progress may, in some cases, be limited by lack of specific understanding of the disorders and the types of strategies that would best facilitate the child. Staff are always very welcoming of specialist consultation, but for those children with ASDs who may need one to one attention, their needs may not be well met in this setting.. The level of accommodation is also inadequate in some situations.

Families have been pleading for a range of mainstream supported and specialised early education programmes. Many have opted for a combination

of any available specialised service, e.g. some degree of in-home programming, and part-time attendance in a mainstream setting. This can only be accomplished, however, in families with the requisite emotional, financial and practical resources. Precedence for in-home teaching was set in the 1993 SERC document:

Parents of pupils with severe or profound mental handicap should be assisted in implementing in their homes the education and training programmes which are being provided...

This should be extended to children with an ASD, provided it is included in their formal plans (see 5.8.2). Comprehensive home programmes for the youngest children are particularly relevant.

RECENT DEVELOPMENTS

- 7.2.1 In the past two years, the Department of Education and Science has opened three preschool classrooms for children with autistic disorder in mainstream schools in Dublin, two on the Northside and one on the Southside. Students attend on a Junior Infant's time schedule. Initially the classes insured intensive input in the classroom, through flexible scheduling so that there were no more than four students present with three staff until the children were well integrated. This was seen as a long overdue but more than welcome initiative. Parents report a high level of satisfaction with these classes. Unfortunately, there has been little specialised early intervention training for the teachers, no defined intervention programme for them to follow, no 'treatment' outcome evaluation process in place, and little to no progress in adding to this very low number of available places.

The CABAS project in Cork (the Comprehensive Application of Behaviour Analysis to Schooling programme) was established by the Department of Education and Science as a 5 year pilot project in 1999 to inform future practice and includes children from three-six years old. This is a very highly structured system which applies the principles of operant conditioning to teaching in the classroom and in the home during a full school day and extended school year. Home visits with parent training are also incorporated into their approach. Non-teacher staff who have undergone a CABAS specific training programme implement the assessment-based plan in a 1:1 format of repetitive drills according to 'Precision Teaching' procedures, recording the student's performance on each trial of every task. They work under the on-site supervision of a more experienced trainer and a behavioural psychologist. Recently one qualified teacher was appointed, so for the majority of the time the project has been running, there were none, and, through no fault of their own, there was no integration with the mainstream students. An inclusion project is being planned for Autumn 2001 (see 6.10). Parents of children attending CABAS report a high rate of satisfaction with their children's rate and amount of progress. Outcome studies from CABAS itself support their approach for pre-academic and academic skill acquisition (CABAS, 1996). An external evaluation of the project and approach as a whole from an outside

source was originally planned, and in fact was requested by CABAS themselves, from the beginning of this project, and was recently initiated.

- 7.2.2 Guralnick (1994) emphasises the benefits of early education occurring in integrated settings:

Positive outcomes are manifest in more constructive social interaction with peers, more complex play behaviours and... communicative competence...

If the recommendations of the Task Force Report are to be realised, the implementation of early education policy must be afforded a priority that has previously not been seen in this country. In assigning this priority status, it must be acknowledged that the attitudes, understanding and knowledge of some persons administering programmes for children with an ASD must change to reflect this emphasis, current knowledge and needs.

7.3 THE VALUE OF EARLY EDUCATION

“If children with autism are not given individual attention they may revert to their own repetitive activities or solitary existence” (Baron-Cohen 1993, p16).

- 7.3.1 The nature of autistic spectrum disorders has been described in previous Chapters, and it is accepted that it affects the developmental processes of the child throughout life and consequently inhibits learning. In order to provide an effective educational service for children with ASDs, it is fundamental to understand and identify their needs.

Based on submissions received, research conducted for this report, and experiences of Task Force members, it is the overwhelming consensus of the Task Force that the earlier a child receives educational and clinical intervention, the more likely the communication, language and social imagination impairments will be lessened and prognosis improved. This will be costly, but worthwhile. For children who receive intensive treatment from the age of two, the prognosis may be greatly improved. Although many children will not become fully independent in adulthood, it is hoped that their level of dependency will be significantly reduced. It is also expected that early education may increase the child's likelihood of progressing toward full inclusion during primary school.

The provision of pre-school/early education was presented in many submissions to the Task Force as an integral and essential part of early intervention. A review of the literature indicates the critical importance of early intervention as central to the future development of the child with special educational needs. Early intervention can be defined as:

...involving systematic strategies to support the optimal development of young children with special needs and to enhance the functioning of their families and caregivers (Mitchel and Brown, 1991).

This premise is most significant for children with an ASD. The SERC Report (1993) regarded identification and intervention early during the pre-school period as a *first priority* for children with autism. The Task Force endorses the concept of early intervention as a vital aspect of pre-school provision, in particular, for children considered or suspected of having an ASD.

7.3.2 For the maximum benefit of a child with Autistic Disorder, published studies, primarily associated with the intensive behavioural model of intervention (see 6.3.1), but not exclusively (e.g., Strain, et al, 1985), suggest that programming be initiated and be most intensive between the ages of two and four years. Reported gains have consistently been better for the younger age groups. Studies to date have not included children with an ASD under the age of two, so the Task Force cautions the Department of Education & Science in this regard, and as stated elsewhere, strongly recommends educational and clinical interventions be initiated from the point of diagnosis. Outcome research in Ireland for the younger ages, is also recommended.

7.3.3 Neuro-psychological research on the structure and functioning of the brain also supports the concept of early intervention. The neural systems approach to learning:

... assumes that overt behaviours are the product of internal mental functions and that these ... arise from the operation of neural systems and their interconnections (Gordon 2000, p. 503).

Outcome studies of pre-school programmes reviewed by Dawson and Osterling (1997) found that well-planned approaches based on different theoretical and philosophical beliefs, and varying strategies of intervention, all had positive outcomes for not all, but a substantial number of the children involved. A recent evaluation of pre-school provision in Northern Ireland for children with an ASD reported positive outcomes for TEACCH programmes when used appropriately (Sheehy, 2001).

7.3.4 Any child who is suspected of being on the autistic spectrum therefore, must be eligible for clinical and educational services. Children are sometimes now suspected and at times diagnosed as early as eight months, and a definitive diagnosis can very often be made by twenty-four months. A definitive diagnosis should not, however, be required to avail of specialised education and clinical support.

7.4 EARLY EDUCATIONAL APPROACHES

7.4.1 There is very strong support that planned interventions using sound theories of learning result in significant improvements in many young children with an ASD (see 6.3). While it is acknowledged that some children will benefit from

highly directed intensive intervention, the submissions to the Task Force commented on what contributors see as the appropriate content of early intervention. The main points made were that intervention should be:

- intensive (this has different meaning in different approaches)
- comprehensive
- linked to individualised needs
- holistic

In all cases, a proven, well defined and well delivered method of instruction should underpin all educational interactions with children with an ASD.

The information presented above, including that describing the workings of the neurological system, have implications for ‘where’ we place the emphasis in early education. Most parents and teachers request intensive Speech and Language Therapy as the first and primary intervention. If ASDs are considered from a neuro-developmental perspective however, Occupational Therapy, Physical Education and normal pre-school activities would be considered equally necessary and would actually enhance the role of the Speech and Language Therapist. Once the child’s neurological system is functioning more efficiently, they would be in a much better position to benefit from a clinical communication input.

...attempts to improve such an (ASD) individual’s overall communication and language abilities have to improve the function of a number of distinct underlying abilities and their neural substrates. The individual’s ability to learn how to learn must (first) be improved...the function of each component process in the chain of processes involved in communication and language must be improved (Gordon 2000, p. 504).

It is appropriate therefore, to suggest that individual, ongoing, in-depth multi-professional assessment is central to establishing an effective programme. The Task Force regard this as best practice.

7.4.2 Intragency co-operation is vital during the early years. The service should go to the child and family and the disruption and demands on the family in securing services minimised. Collaboration will ensure that the child and family is not either under-served or conversely, overwhelmed. Various ‘packages’ to meet the variety of needs presented by children and families must be developed. For example, an initial ten week home programme might be appropriate for many of the very young children and parents. The levels of clinical and educational support, and the locations in which these are provided will vary from family to family based on the child’s and family’s needs. Thus a variety of options must be developed and made available to accommodate the individual needs presented. The full range of needs must be addressed including medical, dietary, behavioural, social, emotional, recreational, educational and future-planning. Parent and sibling needs must also be identified and accommodated. Once again, this will require close collaboration

between the Department of Education and Science staff and Health Board staff members.

- 7.4.3 The importance of liaison between educational and Health Board psychologists in respect of children under the age of 5, was recognised by the SERC report (1993) which stated:

The School Psychological Service should have a joint involvement with the Health Board pre-school assessment and advisory services, in consultation with parents, when a decision on the initial school placement of a child with a disability is being taken.

In the event that the remit of National Educational Psychological Service is extended to cover children under age 5, it is anticipated that the relevant Clinical and Educational Psychologists will work closely together on a collaborative basis, in relation to children with an ASD. Any agreed transfer of responsibilities, e.g. from the Health Board to the NEPS psychologist, should take place over a period time to insure a smooth transition for both child, family and involved staff. As noted elsewhere in this report, the National Educational Psychological Service is not yet sanctioned by Government to provide services for preschool children. Any decision to extend the remit of the National Educational Psychological Service to provide services for preschool children, will have staffing and resource implications.

7.5 EARLY SERVICES APPROACHES AND CURRICULUM

- 7.5.1 There are a number of projects that have been developed to work with children with an ASD in a comprehensive way. They ordinarily include home programmes, parent education, child-specific training, and inclusion with a peer group, either normally developing or 'special'. Others focus on one primary mode of intervention. Examples of these are:

- Applied Behaviour Analysis Programmes (ABA) (see 6.3.1):
 - a) Behavioral Intervention Association (BIA, San Francisco, CA, www.bia4autism.org)
 - b) The Comprehensive Application of Behaviour Analysis to Schooling programme (CABAS);
 - c) The London Early Autism Project - LEAP Outreach Project;
 - d) Parents for the Early Intervention of Autism in Children (PEACH, UK);

- Developmental, Individual Difference, Relationship model (DIR, Greenspan, 1997): adults are encouraged to spend six to ten 20-30 minutes sessions daily interacting with the child, typically on the floor (inadequate evidence to recommend this model).

- EarlyBird: a three month autism specific parent programme which combines group sessions with individual home visits utilising video

feedback; provides an understanding of ASDs, and training in communication and behavioural systems; aimed at supporting parents and children between the time of diagnosis and school placement (UK).

- Hanen (adapted): a communication programme based on examining videotapes of interactions between the adults and child, identifying the child's communicative intent, and having the adult learn to observe, wait for a response, and follow the child's lead. (see 6.5)
- High Scope/Bright Start - based on the constructivist theory of early development, where the children, through language and social mediation, must make explicit which activities they want to be involved with, are then adult led through support and demonstration, and then reflect on it with peers and adults, which requires use of memory skills and self-awareness. The environment is divided into distinct areas and is well planned.
- Keyhole Project - a PAPA and University of Ulster program for 2 ½- 3 ½year olds where a Domiciliary Therapist provides eighteen two-hour home visits over an eleven month period for assessment, goal setting, parent training and intervention, based on the TEACCH model. The child must have a confirmed diagnosis of autism and must not be attending any other pre-school service during the first four months.
- LEAP: An Alternative Programme for Pre-schoolers and Parents. Consists of an integrated pre-school programme with typically developing children and children with an ASD, and a behaviour skills training programme for parents. A family service co-ordinator assists in insuring skills and behaviours are taught in natural contexts (positive outcome research - see Strain, et al, 1986; Odom & Strain, 1987).
- Music Supported Communication - teaches early interactive skills and spontaneous communication by using the structure of music to make social signals salient for the child and to make social behaviour meaningful and enjoyable. An evaluation of this approach as an early intervention is in press (Chandler et al. - for *Autism*).
- Picture Exchange Communication System – PECS: helps preverbal children with autistic disorder to initiate requests and communicate needs through a six phase system (see Chapter 6.5).
- Portage Project: based on developmental areas and sequential activities and carried out at primarily at home though also used in classrooms.
- Son-Rise/Options Institute: encourages the parent to become part of the child's world; the child becomes the teacher (see 6.2.2).
- TEACCH: a highly structured system of visual organisation (see Chapter 6.3.2).

- Touch Therapy: a method of massage involving specific sequencing of body parts (no adequate evidence for its use).
- Walden: sets up an integrated pre-school classroom with four learning zones, each having a set of goals and a teacher. Children move amongst the zones and activities and approaches are individualised. The focus is on the development of language and social skills through 'incidental teaching' (positive outcome research - see Handleman and Harris, 2000).

Some of the above also include curriculum guides. Handleman and Harris (2000) include relatively thorough descriptions of nine early services programmes in the United States that would be considered good, data based treatment models. Another useful tool for parents in particular, is HELP at Home: The Hawaii Early Learning Profile (annarbor.co.uk). It provides normalised activities for each stage of development across a number of areas, from birth through a developmental age of 3 years in one guide, and 3-6 years in another.

7.5.2 Programmes which report significant positive outcomes are high in adult:child ratios. To accomplish this, the majority of them reinforce their staffing pattern with undergraduate and graduate students from nearby universities. Handleman and Harris (2000) state:

This is a valuable and inexpensive potential resource that every program should consider. Not only do the children benefit from the presence of energetic undergraduates, but the college students benefit as well through the opportunity for "hands-on" learning. In our own day school at Rutger's University... scores of undergraduates have remained in the field of developmental disorders after their experience at our centre (p. 2).

This should be pursued in Ireland with the teacher training college programmes, child care training programmes, universities with departments of psychology and education, and with Montessori training institutes (see chapter 12). This would assist with offering the 1:1 ratio in special classes or homes where recommended, as well as providing trained support workers/classroom assistants to children with an ASD in their mainstream class settings. Research and evaluation would also be a strong component of the Department of Education and Science early services and University ASD programme affiliation.

7.5.3 Teaching the child to play with objects and others, is a critical component of any early services programme. Additionally, given what we know about normal childhood physical activity facilitating the growth of neurons and consequently improved neurological patterns, structured gross motor activities are vital on a daily basis. Music is often a natural accompaniment to some physical activities, and can provide another sensory input of benefit to the child. Incorporating various kinaesthetic stimuli, e.g. sand, water, can increase attention to objects and activities, as well as having a positive affect with regard to sensory integration. In summary, all of the things that normally

developing children are interested in and that are offered to them in pre-school programmes, will be of benefit to the child with an ASD. The difference will be in the planning, manner and frequency of delivery of these normal activities.

Core elements in effective early intervention for planning and auditing purposes are:

- individualised provision incorporating the key needs of social interaction, play and communication;
- appropriate and intensive support;
- comprehensive analysis and application of assessment and intervention findings.

1. 7.5.4 In order to meet the requirements of intensity of special programmes, the length of the school day, or generally, the number of hours per week a child is engaged in their special educational programme, must exceed those typically afforded children under the age of six in Ireland. 'Early Start' and 'Junior Infants' classes are of two-and-a-half to four hours duration. While this time scale may be appropriate for some children with ASDs in mainstream or Montessori pre-school placements, many other children with an ASD require a greater level of intensity to benefit from intervention. The Task Force recommend that the school-day should be available, at a minimum, from 9am-2.30pm, or for the equivalent, with hours of attendance arranged on the basis of assessed needs or in accordance with the wishes of the family. The need for after school, holiday and summer programmes to insure maintenance of skills and knowledge, is also acknowledged and highly supported by the Task Force. These recommendations should apply to all locations in which a child with an ASD attends, e.g. Learning Disability service, Health Board pre-school, as well as designated Department of Education and Science classes and programmes. In some cases, as noted below, the hours may be spread over two to three locations, as determined by the child's Statement of Educational Need.

- 7.5.5 The Clinical Practice Guidelines (New York State Department of Health, 1999), is a good resource for medical treatments often associated with ASDs. They make recommendations for and against particular educational and medical treatments based on published research results.

Dawson and Osterling (1997) cite the following as necessary components to effective intervention for children with an ASD under aged six:

- Curriculum Content which includes:
 - attending skills
 - imitation
 - how to play with toys
 - how to interact with others
 - comprehension and use of language
- Provision of a highly supportive environment which includes generalisation strategies;

- Provision of predictability and routine;
- Following a functional analysis approach to challenging behaviours;
- Provision of transition skills to help the child move from one activity to another, one place to another, one program or type or classroom to another;
- Involving the family;
- Intensity of intervention (at least 15-20 hours per week of school-based intervention);
- Provision of an augmentative communication system;
- Provision of Occupational Therapy;
- Integration with typically developing peers *in the classroom*, and a trusting, positive social relationship with adults involved;
- The following skills are identified as necessary for success in inclusive settings so should be emphasised in the special needs setting:
 - Co-operating with requests from adults
 - taking turns
 - attending to directions, from near and afar
 - sitting during activities and remaining quiet
 - raising hand to request attention
 - walking in line
 - putting toys away after use
 - communicating basic needs

The Douglass School programme (Handleman and Harris, 2001) also includes in their curriculum:

- Independent work skills (TEACCH also emphasizes this)
- Conceptual and reasoning skills
- Visual perceptual and visual memory skills
- Auditory perception, auditory memory and auditory closure
- academics
- fine motor manipulation, including writing
- gross motor movement and object movement
- self-help skills

Other programmes highlight additional curricular components, e.g. Science, with related age-appropriate activities.

7.6 BEST PRACTICE

7.6.1 The State must invest significant resources into the development and implementation of early services programmes for children on the Autistic Spectrum. In order to be effective and successful, early services should be well established, easily accessed and responsive to a number of principles. Agreement among researchers and practitioners reveals that appropriate intervention should begin by twenty-four months (the Task Force recommends at the point of diagnosis) and should include as guiding principles:

- the establishment of clear procedures based on the statutory right of the individual to access appropriate services;
- independent multi-professional assessment that includes parents;
- an individual education and social plan to determine the intervention provision;
- baseline and continuous measurement;
- appropriate advisory support;
- effectively trained professionals to deliver the programme of intervention;
- parental involvement and training in the education of their children;
- current research thinking;
- a range of intervention approaches and strategies (see Chapter 6);
- effective deployment of a number of professionals such as Teacher, Behaviour Specialist, Speech and Language Therapist, Occupational Therapist, Psychologist and Social Worker who are educated in ASD and collaborative working;
- an independent appeals procedure for parents.

The London Early Education Project in their Task Force submission proposes that the chosen approach should have:

- *A sound theoretical base*
- *Sound methods of assessment and evaluation*
- *An evolving broad and appropriate curriculum*
- *Good ongoing research*

7.6.2 Based on materials and practices reviewed by the Task Force, the following characteristics are also recommended for any ASD pre-school programme:

- Low student: teacher ratio (no more than 2:1)
- Observation of and learning from the child
- Order: organisation and structure
- Repetition
- Expecting progress
Pitching language and activities to child's current level of understanding and ability
- Individualising within the classroom program
- Normal, developmental activities

The principles advocated for quality early services programmes for all children should also be incorporated in respect of ASDs. Amongst others, Pugh (1999) includes the following:

- clearly defined aims and objectives;
- an effective management structure;
- close relationship between staff and parents, and the involvement of parents in the running of the service;

- a broad based, balanced, and relevant curriculum, appropriate to the physical, emotional, spiritual and physical development of children, informed by observation and assessment;
- evidence of children being actively involved in their learning, with a strong emphasis on play and talk;
- well trained staff who can understand and respond to the needs of individual children and structure and support their learning;
- continuity of care through a key worker system;
- a staff development plan, which ensure access to regular support and training for all staff;
- a well organised physical environment, with access to appropriate resources inside and out;
- liaison with others involved in the child's health, care and education in the local community;
- a system for monitoring and review of provision.

7.6.3 There is a need for the recommended Department of Education and Science/Health Board joint ASD planning committee to agree to a basic, formal set of procedures and interventions to be offered to all children and families in respect of a very young child with an ASD. Programmes referenced herein should be considered as a starting point. Each geographical area should then be equipped with the training, staffing levels and material resources needed to implement the programme to meet their local needs. Based on the Task Force review, we recommend that this programme include the following components, with support as needed:

- home
- classroom
- a mainstream setting (even local Superquinn creche, once per week)
- not less than ten-fifteen hours per week of 1:1 instruction incorporating the principals of learning and reinforcement theory and precision/discrete trial teaching
- significant, planned gross motor activities
- structured activities
- "normal" activities
- a designated curriculum
- sensory integration
- a designated communication programme
- a designated language development programme
- positive behavioural supports (see 5.7)
- instruction in local community settings frequently accessed by the family

As at all other stages, parental consent and training in this process will be of fundamental importance.

7.6.4 To accomplish all of the above will require a low child to adult ratio, particularly as the majority of children in this age group will not yet be toilet trained or independent in other skills of self-care and daily living. It is

therefore proposed that in programmes for children with an ASD aged 5 or under, the ratio of staff to children should be based on the needs of the particular children in the class or programme at the time. For some teaching approaches or circumstances, a 1:1 or at times 1:2 ratio will be required.

All of the criteria identified in this and other sections of this report should be utilised to evaluate the appropriateness and quality of a pre-school service for children on the autistic spectrum. This work could be done in collaboration with the new Centre for Early Childhood Development and Education, announced in September 2001, whose role will be to develop quality standards for early childhood education. A key function of this new Centre, as announced, will be to examine and develop forms of early intervention and support for children from disadvantaged backgrounds and children with disabilities, building on the experience of existing programmes (press release from Minister for Education, September 2001).

7.7 RANGE OF LOCATIONS FOR SERVICE DELIVERY

7.7.1 The Task Force endorses the philosophy of the White Paper, which recommends that early education should come primarily under the Department of Education and Science rather than the Department of Health and Children. The literature supports the notion that the most important variable in the prognosis of a child with an ASD, is whether or not they receive an intensive early education (as opposed to therapy). This does not exclude the need for, or advisability of, including clinical components in the educational programme, but clearly prioritises the normal developmental tasks of early childhood on a daily basis. This is best accomplished in a setting with daily access to a normally developing peer group (Strain, 1985).

7.7.2 Issues relating to making a choice of school placement are raised in eight Task Force submissions. The wish to have a choice is captured well, perhaps, in the comment from a parent who wants the:

freedom to choose the type of education you want for your child - like regular children.

A service provider in the UK stated in their submission that in their experience, parental choice has an impact upon the level of parental involvement and subsequent success of a pre-school programme. There is research to support this (Murray 2000 bibliography). This reinforces the importance of parental agreement and satisfaction with the services being offered.

7.7.3 Early services may be delivered in a variety of settings, and in any combination of settings. These will be determined during the initial and updated intervention plans, with the necessary level of support provided for each. The Task Force embraces the concept presented by Dr. Phillip Strain, University of Colorado, that 'special' is not a place, but a set of services. As such, they follow the child wherever s/he may be.

Examples of settings are:

- In-home
- Community play groups
- Community pre-schools
- Health board pre-schools
- Montessori schools
- National school special classes
- National or private school mainstream Infant classes
- Special schools
- Voluntary programmes for children with intellectual disabilities
- NGO programmes for children with intellectual disabilities
- Approach specific programme

It is the Task Force's conclusion that early services placement should be agreed at the point of assessment and diagnosis, written into a formal, statutory statement of need, and facilitated by Department of Education and Science special needs staff. Parents should not have to seek a place to receive services on their child's behalf.

- 7.7.4 Plans to educate and facilitate mainstream settings, students and staff where a child with an ASD is involved, must be included in the service delivery plan. The Department of Education and Science should consider forming a partnership to well resource and support a range of existing pre-schools (e.g. accredited Montessori schools), to provide integrated pre-school experiences for children from point of diagnosis through five years of age, with ASD specific supports funded by the Department of Education and Science. A set of standards would need to be defined in this regard. We do believe, following our research on the Task Force, that in as far as possible, children with an ASD should be included in existing mainstream pre-school services. In any case, the educational support plan developed must be intensive and supported by persons with expertise in the methodology/methodologies being utilised.

The Department of Education and Science Inspectorate must play an active, well defined role in the joint (with Department of Health and Children staff) inspection, promotion, monitoring and evaluation of programmes for young children with an ASD. Annual reporting should be conducted. Additional numbers of Inspectors, some of whom must gain expertise within the area of educational provision to children with an ASD, are urgently required. The role of the proposed Special Needs Organisator also needs clear definition with regards to setting up and implementing the range of pre-school programs recommended (See Chapter 13 of this Report). In the interim, they should be extremely pro-active in the development of both special classrooms and integrated options for the under five year olds currently seeking full or partial out of home programming.

7.8 RECOMMENDATIONS FOR EARLY SERVICES:

The Task Force recommends:

1. that the State put significant resources into the development and implementation of intensive early services programmes for children on the Autistic Spectrum;
2. that the Department of Education and Science, in conjunction with the Health Boards and in consultation and agreement with parents, develop protocols for nationally agreed intervention models to be developed in each region;
3. that educational (i.e. under the Department of Education and Science) and independent clinical (i.e. under both the Department of Education and Science and Health Boards) assessment and intervention be offered from the point of diagnosis;
4. that special classes specifically developed for children with an ASD aged five and under, be established in mainstream and some special schools, and that these be differentiated on the basis of need and level of functioning;
5. that pre-school children with an ASD be eligible for provision under the home tuition scheme;
6. that children be allowed dual enrolment, i.e. in a mainstream setting as well as a specialist ASD class;
7. that statements of educational need, individual educational plans, and child and family support plans be developed for the young child;
8. that individual, ongoing, multi-professional assessment be offered to establish effective, sequentially ordered intervention programmes;
9. that the Department of Education and Science Inspectorate play an active, well defined role in the promotion, monitoring and evaluation of ASD early services programmes;
10. that the Department of Education and Science form partnerships in order to adequately resource and support a range of existing preschools and to provide integrated preschool experiences for children from the point of diagnosis to five years of age, with ASD-specific supports funded by the Department of Education and Science; that a set of standards, guidelines and monitoring procedures be defined to accompany this development;
11. that formal links between the Department of Education and Science, Health Boards and Universities with Education and Psychology Departments be established for the purposes of developing appropriate early education for children with ASDs;
12. that NEPS be authorised to become involved with preschool and early services programmes;
13. that supports be provided as needed for children with an ASD when in a mainstream setting;

14. that the Visiting Teacher for ASDs Scheme, suggested in this Report, be available to children with an ASD in all preschool settings;
15. that special pre-school classes offer validated approaches of teaching children with an ASD;
16. that the Department of Education and Science provide the staff necessary to conduct home and school programmes, including intensive behavioural intervention where and to the extent indicated; that this could be conducted in approach specific (e.g. Applied Behavioural Analysis) schools or classrooms;
17. that prescribed therapies and behaviour management support be made available, and delivered as agreed on the Support Plan or IEP, regardless of where the child receives his/her education;
18. that formal review be conducted at least annually at this age;
19. that the NEPS be involved, in collaboration with the relevant Health Board psychologist, in the placement and subsequent monitoring of children aged 5 years and under who have an ASD;
20. that independent evaluation research on pre-school programmes funded by the Department of Education and Science and, where relevant, by the Department of Health and Children, be conducted to inform future planning and provision.

CHAPTER 8

PRIMARY EDUCATION

8.1 INTRODUCTION

This chapter will review the current range, and the associated inadequacies, of educational provision and support services for primary school children with ASDs in Ireland. It will make suggestions regarding primary curriculum and it will outline a new range of proposed options to meet the needs of children with ASDs, in the context of an individual education plan. It will also outline what the Task Force on Autism perceives as good practice, taking into account the submissions received as well as additional information accessed in the course of the Task Force's work. Finally, it will comment on collateral needs. The chapter ends with a list of recommendations.

8.2 CURRENT PROVISION

8.2.1 Educational Provision

In October 1998 a government decision led to the recognition that all students with disabilities within the mainstream national schools system have a right to automatic provision to meet their needs. Students with disabilities and special needs who attend mainstream schools now receive support, in the form of additional individual teaching and special needs assistant services. DES circulars 8/99 and 9/99 set out the procedures to be used by the authorities of national schools in applying for additional support in respect of such pupils.

At present educational provision for children with ASDs is made in a variety of school settings (in cases where children with ASDs are enrolled in special classes, the maximum number of pupils per class is six and staffing for such classes consists of one teacher and two special needs assistants. Enhanced capitation grants, start-up grants, computer grants together with specialised furnishing grant also apply in such cases):

- in mainstream classes, with additional support - this support consists of additional teaching hours from a Resource Teacher (to a maximum of five per week), support of a Special Needs Assistant (full-time, if necessary) and computer equipment grant as recommended in the relevant assessment reports;
- in three special classes specifically for children with Asperger's Syndrome in two mainstream national schools;
- in thirty-six special classes for children with ASDs in twenty-four mainstream national schools;

- in thirty-five special classes for children with ASDs in twenty-two special national schools, which cater mainly for children with either mild or moderate general learning disability;
- in two special schools for children with ASDs;
- in one special school for children with emotional and behavioural disorders;
- in special schools for pupils with general intellectual disability other than in special classes in those schools;
- in special schools for children with emotional and behavioural disorders;

Further details of the provision for children with ASDs is provided in the Appendices. Appendix 12 gives details of sanction conditions for the establishment of a special class for children with autism. The circulars of the Department of Education and Science which set out the procedures to be followed by schools in applying for a resource-teacher service or for a special class are included in appendix 11. A list of special classes is presented in appendix 13. Appendix 14 gives details of the equipment grant for special classes for children with ASDs.

Educational provision is also made for a small number of pupils for children with ASDs through the home tuition scheme of the Department of Education and Science. This scheme was originally designed to cater for children who were unable to attend school, for a prolonged period, because of ill health. In more recent years this scheme has been availed of, in exceptional cases, to provide a home teaching programme for a small number of children with ASDs.

All children with special needs, who are enrolled in special schools or special classes, are entitled to avail of special transport which is operated by Bus Éireann on behalf the Department of Education and Science. The Department of Education and Science also makes funding available to school authorities for the provision of escorts on all special transport. In exceptional cases, when circumstances make it impossible to provide special transport in the normal fashion, a transport grant is available to parents/guardians of the pupil to assist with the cost of making private transport arrangements (see below for further details).

8.3 REVIEW OF CURRENT PROVISION- PROBLEMS AND INADEQUACIES

8.3.1 Lack of Data and Planning

The concept of ‘entitlement’ referred to in Department of Education and Science circulars 8/99 and 9/99 is a very welcome step towards the acknowledgement of Irish children’s rights to receive an appropriate education. However, it must be acknowledged, on the basis of evidence available including that of submissions made to the Task Force, that educational provision for children with ASDs in Ireland to date has, for the

most part, been grossly inadequate. It must also be stated, to the extent that provision has been made either in mainstream or in special settings, that it is unevenly distributed across geographical regions. Until 1998 there was only a minimal level of special provision for children with ASDs at the primary school level. This provision included two designated schools, both located in Dublin. Nevertheless, even in the Dublin area, many young children remained on waiting lists until they were six or seven years old. Unfortunately, in spite of increased provision since 1998, information available to the Task Force indicates that this situation still pertains, in the Dublin area and throughout the country, for many children both at primary and at secondary level. Furthermore, there are still some children who are of school-going age but for whom no appropriate mainstream or special class/school provision exists in their locality.

It is the view of the Task Force that the main reason for this situation is inadequate planning, insufficient funding and the lack of response to research over past years. The result is that appropriate structures are not yet in place for key processes such as pupil-referral, diagnosis, personnel training and support for schools. The seriousness of this situation is further exacerbated by the dramatic increases in prevalence figures, which are being reported, from reliable sources, on an almost daily basis.

The Task Force is now hopeful that the recommendations of this report, along with those of the recently-published Cromien Report (incorporating, in turn, the recommendations of the internal Department of Education and Science report, *A National Support Service for Special Education for Students with Disabilities*), will allow these and other shortcomings to be addressed.

8.3.2 Problems Associated with Current Provision

- The current range of provision and associated supports, at primary level, is inadequate. A wide and creative range of differentiated provision is now required, in a variety of settings, in order to cater for children with ASDs from one end of the spectrum to the other.
- Submissions indicate that current provision for children with ASDs is perceived to be quite uneven and to vary widely from one location to another and from one school or classroom to another;
- Where provision has been made for children with ASDs, opportunities for meaningful integration/inclusion have been extremely limited;
- Some special transport arrangements have been unsatisfactory and have been the source of major problems;
- In all but a small number of cases, parents have no choice regarding where their child attends school or the method in which they receive instruction. In this regard, parents report significant difficulties accessing accurate information about the advantages and disadvantages of recommended

placements or methodologies. This situation is in direct conflict with the terms of the Education Act of 1998, Part 1, Section 6, one of the objects of which is “to promote the right of parents to send their children to a school of the parents’ choice.....”

- The DES has not yet put in place a transparent and effective system of evaluating the adequacy of support for children with autistic disorder or AS/HFA in mainstream classes.

8.3.3 Problems Related to Provision for Children with Asperger’s Syndrome/High Functioning Autism (These problems may not be associated exclusively with this group. Some of the difficulties raised have particular relevance for children with AS/HFA but those associated with placement in mainstream classes apply to all children with ASDs in such settings)

The problems identified include the following:

- Submissions to the ATF indicated that in many cases, children with a diagnosis of an ASD have been placed in ASD-specific classrooms without regard to their level of cognitive functioning. These decisions have had more to do with the actual existence of a vacancy in the particular class for children with ASDs than to admission criteria. Some submissions expressed the view that such criteria were, in fact, non-existent. This has led to a situation, as described in some submissions, in which a number of special classes for children with ASDs have had to cater for a wide range of ability, from children with severe intellectual disabilities to those with average and above average intellectual ability.

Individuals with AS and their families have had to contend with the fact that public awareness of this condition, including its unique disabilities and strengths and the resources available for educational and other services, is limited. The recent proliferation of parent support groups coalescing around the terms ; Asperger syndrome', 'high functioning autism', or ' high functioning pervasive developmental disorders' reflect the fact that individuals with AS have in the past been offered a choice between insufficient services for students with academically based learning disabilities, services for children with autism who are at a much lower level of general functioning, or, still, services for children with conduct problems, whose needs are totally different and incompatible with AS (Klin & Volkmar, 2000. p.363).

Whilst the classes are a valuable resource and are highly beneficial for some children with ASDs, there are strong reservations regarding the ability mix in some such classes and particularly regarding their suitability for AS/HFA children. Problems that have been identified in such classes include:

- children with an autistic disorder combined with a general learning disability have, to date, significantly outnumbered the children with Asperger's Syndrome/High Functioning Autism in ASD classes;
- -academically able AS / HFA students, may not be sufficiently challenged or stimulated, and to date, have not had appropriate access to the normal curriculum in ASD classes
- there is insufficient interaction with peers for the development of many everyday, normal independent living skills and normal social peer behaviours;
- students of high ability may be painfully aware of the segregation imposed;
- students approaching adolescence may become increasingly aware of their marginalisation and may not feel appropriately placed in this setting;
- teachers familiar with classic autism may overlook or may not be sufficiently aware of the subtle but seriously handicapping impairments and difficulties experienced by children with AS/HFA;
- for some children in these settings, there may be a risk of regression, de-skilling, literacy reversal, anxiety and boredom which, in turn, may result in challenging behaviour leading to possible inappropriate or unnecessary chemical intervention.
- strategies and methodologies employed by teachers in existing ASD classes tend to reflect the needs of children with classic autism for whom these classes were originally designed. This is problematic due to the differing cognitive and behavioural profiles of students with autism /AS
- Mainstream enrolment of children with AS/HFA has been confined almost entirely to placement in mainstream classes with the additional support of resource teachers and, in some cases, classroom assistants. The current provision in mainstream classes for children with ASDs, and for AS/HFA children in particular, is considered to be inadequate and must be addressed.
- There is a lack of separate and differentiated special classes for those whose assessed needs suggest that this is the most appropriate provision.
- The potentially disastrous implications of peer rejection, isolation and loneliness of many children with AS/HFA needs to be properly recognised and addressed.
- Appropriate guidelines for the prevention of bullying should be drawn up and implemented.

- Information and training opportunities, material resources, and advice on ASDs (and on AS/HFA in particular) should be made available to resource teachers and mainstream teachers.
- Special classes have not been available as an option, outside the Dublin area, for children with AS/HFA.
- Submissions to the Task Force have made it clear that parents of children with AS/HFA experience a variety of complex and unresolved problems with regard to the educational placement of their children.
- The DES has not identified students with AS / HFA enrolled in mainstream classes, and therefore has not to date, monitored the progress of this group.
- The educational policy of the Department of Education and Science is based on “inclusion in the least restrictive environment” and many children with AS/HFA can do well in mainstream settings, if supported appropriately. However, when parents choose to have their children educated in mainstream classes, they do so in the knowledge that their children are then denied access to the therapeutic and ancillary support that they require.
- For parents who live outside the outside the Dublin area and who have children with AS/HFA, the possibility of accessing a special class for AS/HFA, if such is required, is not within their range of options. Thus they have to choose between an autism class or learning disability class, if available, with the knowledge that neither will address the cognitive abilities and that the latter cannot provide the social, communication and real life adaptive skills that their children need.
- Many children are diagnosed with AS/HFA during the course of mainstream primary education. In such cases parents regularly find themselves with limited support because intervention services, to the extent that they exist, seem to ‘prioritise’ early intervention measures and often do not stretch to meeting the needs of older children. In this situation, many parents are alone and in the stressful position of ‘having to come up with information’ regarding AS/HFA to pass on to teachers and staff who may not have any knowledge of the condition. This is a significant issue for many parents, who are carrying an enormous burden of care with little or no support. In this situation, it is not unusual for a minority of parents to opt for ‘special provision’ regardless of the actual needs of the child in question.
- When children with AS/HFA are placed in learning disability/autism classes, in the absence of AS/HFA-specific provision, their parents are forced to face the situation that follow-on services will not be available for their children after primary school. While the majority of other children within such classes may expect to have a considerable degree of shelter

throughout their adolescent and adult lives, the organisations that provide the existing follow-on services are unlikely to deem those with AS/HFA as being suitable for such services.

- The problems associated with bullying, peer rejection and the isolation of some children with AS/HFA in mainstream schools is a major factor in the placement decisions that their parents have to make. Many parents are fearful of sending their children to mainstream schools because the vulnerability of children with AS/HFA is rarely recognised and because protection is seriously lacking due to insufficient information and lack of knowledge regarding the needs of such children.
- Children with ASDs in mainstream classes have little or no specialised support. In the majority of cases, their teachers (including resource teachers and special needs assistants, if appointed) have had little or no knowledge of ASDs. The following quotation from a submission by a parent conveys that parent's views on the problems experienced by teachers in such situations:

The teacher and the assistant have been excellent and I could never fault them. This was totally new to them and they really had no guidance whatsoever. The teacher has been left to try to organise a programme herself for B. and literally wing it as best she can. This is not good enough. I believe each child should be assessed in their own right (because every autistic child is different and they all have different strengths and weaknesses) and a programme devised for them and the teacher should be given the psychologist's back-up to implement this programme.

8.3.4 Problems (as indicated by an analysis of the submissions to the Task Force) associated with Special Classes for Children with ASDs

These problems can be summarised as follows:

- overall, teachers and principals report that they feel unsupported in their work with children with ASDs;
- some Principals of schools with special classes point out that a substantial amount of their time has been spent setting up and facilitating these classes, and that they have received either minimal or no support from the Department of Education and Science Inspectorate;
- teachers with, in most cases, only minimal amounts of specialist training or preparation, have been faced with setting up classrooms for groups of pupils with a very wide range of individual needs;
- no specific guidelines on curriculum modification have been made available to schools by the Department of Education and Science;

- since each teacher is responsible for curriculum development and decisions regarding methodology and teaching approaches, this may lead to isolation and difficulty, particularly in the absence of adequate training;
- the lack of guidance has caused confusion and considerable variation in the manner in which education is delivered to children with ASDs in both mainstream and specialised settings;
- teachers and classroom assistants are not well prepared, in most instances, for the teaching of children with ASDs and wished for ongoing guidance;
- where training exists it is of benefit, but there is no evidence of practical follow-up support within the classroom setting;
- only recently have classroom assistants been provided. This has come, however, in the absence of with no training or information on the disorder;
- when a pupil is enrolled, there is no satisfactory arrangement for review. This leads to a situation, for example, where a child can remain with the same class and teacher throughout his/her entire primary education, regardless of changing circumstances and of the make-up or age range of the class;
- teachers feel that they do not have adequate time for joint planning and review of programmes with, for example, other teachers and classroom assistants.

8.3.5 Problems experienced by Parents in relation to Primary School Placement for their Children

The task of finding an educational setting for a child with an ASD was raised in very many submissions. The majority of these submissions were from individual parents or parent groups and, for the most part, they recounted the experiences of parents in arranging schooling and education for their children. While a small number tell of managing quite well, the majority described what, for them, appears to have been a difficult and frustrating experience often undertaken in the absence of advice or useful information. There were very many instances of parents' disheartening experiences while looking for a school or other appropriate educational placement for their child. Some idea of the associated frustration and stress is caught in the comment from the parent of a nine-year old child, who stated:

"I have spent my life trying to find a place for him in our educational system."

Many of the concerns raised in submissions were about securing an *appropriate* educational placement. Some provide accounts of situations where the writer believed the child was not 'appropriately' placed.

Another set of parents refer to the responsibility of having to search for a placement:

...we had to investigate ourselves to find the best place we could for her to go to school.

Issues relating to the absence of choice in seeking a school placement are also raised in a number of submissions. The wish to have a choice is captured well, perhaps, in the comment from a parent who wants:

... freedom to choose the type of education you want for your child - like regular children.

One Parents' Group wrote:

Parents are not always aware of their choices or of the advantages/disadvantages of recommended placements in the context of the changing needs of their AS/HFA children throughout their educational lives. The reality is that parents often have little real input regarding the appropriate options for the education of their children as provision of support seldom reflects need.

Other parents, finding that a special class became available locally as a result of recent initiatives in provision of services, struggled with the question of whether it was the right option for their child after all:

...was this the right place for him? At this stage we really needed some help as to what to do. We had been looking for this class for four years, and now, here it was.

8.3.6 Problems associated with the Identification of, and Agreement regarding Access to, Schools in which Special Classes might be located.

Information available in the submissions to the Task Force suggests that the manner in which schools are identified for the purpose of providing special classes for children with ASDs can be problematic. At the initial stages, this is often based on the availability of space and the willingness of the school to take on a special class. Unfortunately, this approach can rule out some schools in which the philosophy and ethos might be particularly suited to such a provision. It may, in some situations, lead to the establishment of a special class in a school where the overall attitude is less than positive or where the circumstances are not conducive to a successful outcome for the class.

The submissions to the Task Force also indicate that, while most of the selected schools have embraced the children with ASDs, difficulties such as the following, have occurred in some cases:

- The assignment of teachers to the special class has caused difficulties in some schools. In some cases, for example, the only teacher willing to take on the duties may not be the most suitable in terms of experience or overall approach. In other cases, a teacher may agree, reluctantly, to take on the special duties. This situation can sometimes arise even though a suitable but not appropriately qualified teacher is available, for example, when a teacher with good experience in teaching children with ASDs has been trained abroad and does not qualify for permanent employment as a teacher in this country.
- Even though the sanctioning of posts of Special Needs Assistants for special classes is welcomed by schools, such posts can be difficult to fill because of perceived difficulties in relation to levels of pay, security and continuity of service.
- Inadequate support, of a specialised nature, for children with ASDs, and for the teachers of these children, in mainstream schools. This situation also militates against the move to establish further special classes.
- A substantial number of Task Force submissions refer to the continuing lack of productive communication between the Department of Education and Science and the Department of Health and Children and to the negative impact that this situation has on the development of services for children with ASDs in mainstream schools.
- The availability of clinical staff, through the Department of Health and Children, has been extremely limited. This has deprived the children themselves, as well as their parents and teachers, of the essential services and support of Speech and Language Therapists, Psychologists, Occupational Therapists and others.

8.3.7 Problems in relation to the Transfer of Children with ASDs to Second Level Education

There is little or no provision, to date, for second level education for children with ASDs and there is little evidence of any advance planning of this type for children now in mainstream or in special provision at primary level. This situation, while requiring attention for its own sake (see Chapter 9), also needs to be addressed before some the difficulties at primary level can be resolved. Submissions have suggested, for example, that a significant number of children with AS/HFA have dropped out of the educational system, at the point of transfer from primary to second level, due to the lack of necessary preparatory work and support at this crucial time.

The Task Force considers that a full multi-disciplinary assessment should be carried out on each child with an ASD prior to completion of primary education. This assessment should take place not later than January of their final year at this level. The main purpose of this assessment should be to identify an appropriate second level placement. The report and

recommendations of this assessment should also outline the manner in which the second level provision can best make adequate provision for the student.

Following the assessment referred to above, a meeting should be arranged between the parents, teachers and professionals involved to consider future educational goals and objectives for the child in question. The educational psychologist, clinical psychologist, speech and language therapist, occupational therapist and other professionals involved in the multi-disciplinary assessment should work collaboratively in assisting the child's teachers and parents to devise an appropriate individualised education plan.

To the extent possible, students should be included in this process. This latter consideration will be of particular relevance in the case of students with AS/HFA, who should also have an opportunity to take part in decisions regarding the implementation of all specialist provision. When transfer of a child with an ASD from primary to second level is being effected, it is particularly important that the resources/supports already available are, subject to appropriate modification, automatically transferred to the next educational setting, and that the new school authorities are not required to apply for such resources, *ab initio*.

8.3.8 Problems Associated with Support Services

Speech and language therapy, occupational therapy, social work services, and on-going psychological services are dependent on the availability of the relevant professionals through the local health board. Crucially, these services are also dependent, mainly, on the children actually being enrolled in special settings (e.g. special classes) as opposed to being integrated, on an individual basis, in mainstream classes. Furthermore, the clinical services that do exist are unevenly distributed throughout the country and are non-existent in some areas outside of the greater Dublin area. It emerges from the submissions that appropriate and suitably adapted programmes of music therapy, art and physical education/movement are available only on a very limited basis and normally only in special school settings.

In relation to speech and language therapy, in particular, the fact that the Department of Education and Science has not been involved, to date, in the provision of such services is seen as a major obstacle to adequate provision in this area.

8.3.9 Problems associated with Home Tuition

The home tuition scheme, as operated by the Department of Education and Science, has been used in recent years for a much wider range of purposes than those for which funding was originally sanctioned. Children with ASDs have been among those to whom the scheme was applied, in the absence of any acceptable alternatives. It is the view of the Task Force that the current home tuition scheme has too many shortcomings to be of use to children with ASDs. In particular, it frequently places too heavy an onus of responsibility on

parents in relation to the employment of a suitable teacher. Funding from the Department of Education and Science is usually on a quarterly-in-arrears basis or when requested on a monthly-in-arrears basis. Furthermore, while the teacher provides a programme in response to the child's needs, the home tuition arrangements are not usually linked with the overall educational provision for children with special educational needs. However, there is a need for provision of home teaching, as required, in the context of the individual needs of the child and taking into account the circumstances and wishes of the family.

8.4 PROPOSED RANGE OF OPTIONS

The Task Force supports the principle of 'the least restrictive setting'. In this context, a range of differentiated service provision models must be available to meet the wide range of needs of children with autistic spectrum disorders, i.e. autistic disorder, Asperger's Syndrome and PDD-NOS, in accordance with DSM-IV-TR diagnostic criteria for the relevant disorder. There is need for a high level of flexibility in achieving an appropriate match between a selected option, or combination of options, and the needs of an individual child. It should also be remembered that it might never be necessary for some children with ASDs to move away from a fully inclusive setting in a mainstream school. In cases where this is not appropriate, the highest possible level of access to mainstream school must be maintained at all times. In this regard, linkages between all the options must be facilitated by the Department of Education and Science and the school authorities and, for example, enrolment procedures should be modified to allow for dual enrolment as necessary.

In the course of its deliberations the Task Force acknowledged the views of some members that classes for children with Specific Speech and Language Disorders have been found, in the past, to be a suitable setting for some children with ASDs. Therefore, even though not including this in the range of options outlined below, the Task Force suggests that the "special class" option (located in a mainstream school), particularly for children with AS/HFA, should not totally exclude such language classes.

The autistic spectrum includes children with a wide range of adaptive functioning and intellectual ability. Educational provision, including initial class placement and on-going placement should reflect this diversity by taking into account the child's specified needs (see, also, sections on Family Support Plan and Individual Education Plan) and must consider the child's level of intellectual ability. Ancillary support should be equally available and accessible within mainstream and specialised setting.

Children with AS/HFA and children with classic autism have significantly different needs. They should receive differentiated educational provision appropriate to those needs and should not be placed in the same special classes. Criteria for placement in classes for children with AS/HFA will include average cognitive functioning in accordance with DSM-IV-TR diagnostic criteria for Asperger Syndrome.

8.4.1 Suggested Range of Options for Children with ASDs:

- (a) Full-time placement in a mainstream class, with an appropriate level of support.
- (b) Full-time placement in an inclusion class, i.e. a small mainstream class (overall maximum of fifteen children), comprising one to three children with special educational needs together with eight to twelve normally developing children. The class would be taught by two teachers, one a regular mainstream teacher and the other a teacher with additional qualifications/experience in special education.
- (c) Part-time placement, with appropriate support, in a mainstream class, part-time in a special class for children with classic autism *or* for AS/HFA. The division of time between the mainstream-class setting (as well as the activities pursued there) and the special class setting would depend on the strengths and needs of the individual child.
- (d) Full-time placement in a special class (located in a mainstream school) for children with classic autism *or* for AS/HFA.
- (e) Full-time enrolment of children with autistic disorder (with appropriate autism-specific support or with access to a special class for children with classic autism) in a special school for children with general learning disabilities.
- (f) Home-based tuition/programmes, where essential and in line with parents' wishes, to meet the child's needs or for other reasons such as severe transport difficulties.
- (g) Full-time enrolment in a special school for children with classic autism.
- (i) Residential classic autism disorder schools *and* Asperger's Syndrome/High Functioning Autism schools for a minority of children with very significant additional psychiatric, behavioural and/or other assessed needs best met in such a setting. Decisions on this category of placement should be made in the context of the underlying principles outlined in this report and, in particular, should ensure that placement is as close as possible to the child's home, that it will endure for the minimum possible period of time and that only in exceptional circumstances will this be deemed suitable for children under twelve years of age.

Enrolment options outlined above will be considered for individual children on the basis of the diagnosis of the child's specific disorder and in the context of the statement of need and will, furthermore, be subject to annual review.

It should be noted that the Task Force is aware that option (b), above, represents a totally new model of provision in the context of Irish schools. It has been carefully considered by the Task Force and is regarded as having very considerable merit and real potential, not only as a response to the specific learning needs of children with ASDs but also as an effective model for inclusive education.

8.4.2 The Individual Needs of each Child, in the context of the Parents' wishes, must be central to all decisions regarding Educational Placement

Children with ASDs present with a very wide range of social and adaptive functioning, and of intellectual and language ability. In addition, patterns of behaviour and levels of functioning can change significantly in any individual child over any period of time.

Educational provision, including initial and ongoing placement, should reflect this diversity by taking into account each child's specified needs (see Chapters 4,5 and 6), and must always take into consideration the individual child's level of intellectual ability, the severity of the triad of impairment and the child's emotional well being. However, these may change over time.

Most special classes will have groups of children whose individual needs, for a variety of reasons including age, level of functioning and overall development, could extend over a very wide and unmanageable range. It is the view of the Task Force that limitations have to be placed on this possibility in each class grouping. This will ensure that there is as much compatibility as possible between the children and will facilitate the implementation of an appropriate curriculum.

8.4.3 The Statement of Need

The diagnosis and the statement of need will confirm the educational enrolment, the goals that are additional to the Revised Primary Curriculum (1999) and the support services that are required. These will be finalised in agreement with the child's parents through the Individual Education Plan. Regular reviews, on a yearly basis, for example, are an essential element in such plans. However, a review may be required at any time that such is considered to be necessary, for example, if it is felt that a modification of the present educational placement should be considered. In particular, it must be possible for parents to arrange to have a review of the IEP take place if they become concerned about their child's lack of progress.

8.5 PRIMARY CURRICULUM

Whenever possible, the guidelines of the Primary School Curriculum (1999) should be used (Chapter 15.1.4). However, since the majority of children with ASDs, including those with AS/HFA have an uneven learning profile, it is necessary for their teachers to access a range of materials to meet their students' curricular needs. Assessment of all the relevant areas of development, mental health, and learning will determine the level and the particular focus of the teaching in any of those areas. An appropriate curriculum should, therefore, be drawn up, based on the student's present level of functioning, and on the teacher's knowledge and understanding of how the ASD is affecting the child's learning style. This will be facilitated by

additional information from relevant multidisciplinary clinicians and parents. The child's level of intellectual functioning will be one important determining factor regarding the extent to which the Primary Curriculum can be suitably adapted.

For some children with AS/HFA the employment of appropriately modified teaching strategies as well as the addition of relevant components of an ASD curriculum may be required. Many, but not all, such children are able for the academic aspects of mainstream teaching, but their ASD may affect the manner in which they learn or respond in this or in other areas. Therefore, each child's intervention will need to be uniquely designed to fit with his/her particular set of ASD characteristics. There are many additional issues of relevance to the support of students with AS/HFA in mainstream settings and these are outlined elsewhere in this report.

Most children with ASDs will require additions to the curriculum to meet their specific needs. Formal and sensitive teaching of age-appropriate living skills, including those associated with leisure activities, will be required for all children with ASDs. In addition, co-ordinated transition planning, in anticipation of transfer to second-level, will be essential for all children with ASDs as they approach the end of their primary school period.

8.5.1 Recommended Features of a Curriculum for Children with ASDs.

Jordan and her colleagues, in unpublished course material at the University of Birmingham, cite the following features in a curriculum for children with ASDs:

- Child-centred, not subject-centred
- Prioritises communication and interpersonal areas
- Teaches cultural norms and meanings
- Includes functional and life skill from the start
- Incorporates sustained physical activity periods daily
- Teaches the students how to observe and imitate
- Accesses normally developing peers

8.5.2 Curricular Areas

The following learning areas, in addition to reading, writing, and mathematics and other academic skills, should be considered when preparing the curriculum (see also Chapter 6):

- Communication and language
- Computers/computer technology
- Personal care skills
- Cognition/developmental levels
- Social/emotional skills and understanding
- Play Skills
- Sensory regulation

- Motor skills
- Self-help skills
- Independent living skills
- Community based skills
- Social skills Training: groups and individual e.g. Carol Grey material,
- Arnold Goldstein's Skillstreaming series; Social scripting (provision of scripts as to how to act in designated situations), and social autopsies (analysing what happened when something goes wrong)
- Circle of Friends type programme for schoolmates
- Anti-bullying programme
- Behavioural support plans and monitoring
- Self-monitoring programmes
- Behavioural contracts
- Self-care skills
- Age appropriate daily living skills
- Leisure skills
- Co-ordinated transition planning before moving to different school or section of the school.
- Generalisation of learned strategies and social concepts, from the therapeutic setting to everyday life;

8.5.3 Recommended Guidelines for Students with AS/HFA

Positive program specifications based on the work of Ami Klin, Ph.D., and Fred R. Volkmar, M.D. of the Yale University Child Study Centre are considered by the Task Force on Autism to be a valuable resource when decisions are being made on appropriate placements and programs for individuals with AS/HFA. This material is outlined in chapter 6 and the relevant section of the publication is quoted in full, with kind permission of the authors, in Appendix 10. These specifications include information material on:

- general intervention strategies,
- specific interventions,
- general strategies for communication and social skills
- academic curriculum

General Strategies for Communication Intervention and Social Skills

- Explicit verbal instructions on how to interpret other people's social behaviour should be taught and exercised in a rote fashion. The meaning of eye contact, gaze, various inflections as well as tone of voice, facial and hand gestures, non-literal communications such as humour, figurative language, irony, sarcasm and metaphor, should all be taught in a fashion not unlike the teaching of a foreign language;
- the individual with Asperger's Syndrome should be taught to monitor his/her own speech style;

- the effort to develop the individual's skills with peers in terms of managing social situations should be a priority;
- the individual with AS/HFA should be helped to recognise and use a range of different means to interact, mediate, negotiate, persuade, discuss, and disagree through verbal means.

Academic Curriculum

- The curriculum content should be decided based on long-term goals, so that the utility of each item is evaluated in terms of its long-term benefits for the individual's socialisation skills, vocational potential, and quality of life;
- emphasis should be placed on skills that correspond to relative strengths and special interest for the individual as well as skills that may be viewed as central for the person's future vocational life;
- specific projects can be set as part of the person's credit gathering, and specific mentorships (topic-related) can be established with staff members or individuals in the community;
- it is often useful to emphasise the utilisation of computer resources, with a view to:
 - (a) compensate for typical difficulties in grapho-motor skills;
 - (b) to foster motivation in self-taught strategies of learning, including the use of "on-line" resources; and
 - (c) to establish contact via electronic mail with other people who share some interests.

8.5.4 Curriculum Guidelines/Resources for children with autistic disorder

The appendices of this report provide a list of curriculum materials that will assist educators and parents in their development of daily activities to meet the needs of child with an ASD. In particular the following Curriculum Guides are also a valuable source of curriculum materials for children with an autistic disorder:

- *Burger School Curriculum Guide for Teachers of Autistic Impaired Students*
- *Eden Institute Core Curriculum*
- *Pathways to Independence*
- *The Assessment of Basic Language and Learning Skills*
- *Murdoch Centre Curriculum*

In addition, *Understanding the Nature of Autism, A Practical Guide* (Jenzen, 1996) is a comprehensive resource for classroom teachers and is an excellent resource for all teachers of children with an autistic disorder. A further very useful guideline document has been provided in British Columbia - Ministry of Education, Special Programs Branch, British Columbia (2000) 'Teaching Students with Autism - A Resource Guide for Schools', 136 pp, Office Products Centre, 4248 Glanford Avenue, Victoria BC V8W 9V7

The National Council for Curriculum and Assessment is currently reviewing the curriculum for children with general learning disabilities. This process is taking place in consultation with parents, teachers and the other interested groups and the outcome, as well as the future work of the NCCA, will be an important resource and reference for teachers of children with ASDs.

8.6 COLLATERAL NEEDS

8.6.1 The Principal

The role of the principals in mainstream schools that cater for pupils with ASDs changes, inevitably, in significant ways. The administrative duties of such principals include a range of additional duties that make very significant demands on their time and on their expertise as administrators and educators. It is recommended that these additional duties be taken into account by the Department of Education and Science in considering the overall role of the principal and in the allocation of staffing quotas to schools. It is also felt that these principals require direct support from the Department through its Inspectorate and through appropriate advisory services.

8.6.2 Staff/pupil Ratio in Special Classes for Children with ASDs

While the current ratios in special classes may be sufficient for some children with ASDs, there should be formal provision for a further reduction in class size in some circumstances. It is felt, therefore, that the needs of certain children are such that a pupil/teacher ratio of 4:1 (with two special needs assistants, thus giving an adult/child ratio of almost one to one) should be granted, in the context of the assessment of these children's needs. Such an arrangement would allow more time for 1:1 instruction and would greatly enhance the opportunity for social training and community-based training outside the classroom. At present, for example, teachers are very concerned with regard to issues of safety in out-of-school settings, which are essential in promoting generalisation of learning. There are also some children who present with very significant additional individual needs, as outlined in Chapter 6 (*Early Education*), and their needs may be such as to require that staff to children ratios be based on careful consideration of the individual needs of such children.

In general, lower ratios would also allow for more frequent contact with parents and consultation with multi-disciplinary teams. Because of the overall importance of this area of provision it is essential that staff/pupil ratios in individual setting be reviewed, on a regular basis, in the light of the strengths and needs of the children in those settings.

8.6.3 July Provision/Extension of School Year for Children with ASDs

There is considerable concern amongst teachers, principals and parents with regard to the extension of the school year. The basis for such an extension has

been agreed and further negotiations have taken place followed by recent clarification of conditions and regulations in a letter from the Department of Education and Science to school authorities. It is hoped that this progress will facilitate the establishment of an efficient structure that will be acceptable to all concerned in the negotiations. The Task Force fully acknowledges that there is a need for an extended school year, in special classes and schools, for children with ASDs whose parents wish to avail of such provision. The Task Force also acknowledges the progress made to date. However, it is aware of on-going difficulties and it recommends the continuation of discussions so that these difficulties can be overcome.

8.6.4 Physical Resources

Standardisation with regard to physical resources for both schools and teachers needs to be reached. For example, acceptable specifications for designated autistic disorder and AS/HFA classrooms should be clearly established, as well as for any space above and beyond classroom areas, e.g. gross motor area, sensory room, therapy room, outdoor equipment area. A list of furniture, equipment, audio-visual materials, computers and computer software, supplies and reference books and guides should be provided to all schools and teachers establishing a programme for a child with an ASD and should be specific to the particular educational needs of the children attending.

A grant for the purchase of reference books and guides should be provided to all mainstream schools that enrol children with ASDs. This will be necessary to ensure that teaching staff have access to up to date information on ASDs which will enhance their understanding of current theories on mainstream classroom strategies for children with ASDs

8.6.5 Transportation

The Task Force adopts as a fundamental principle that educational provision should be located as near as possible to the child's home. Nevertheless, it also recognises that, for a variety of reasons, optional transport will have to be made available to children with ASDs.

Information from the Department of Education and Science outlines the existing provision of school transport as follows. Children with special needs enrolled in special schools or special classes in primary schools qualify for special transport. Bus Eireann operate the school transport service on behalf of the Department of Education and Science. The Department endeavours to ensure that no pupil is disadvantaged by the distance from a school or by isolation from other pupils with special needs. Where special transport cannot be provided, a transport grant is payable to the parents/guardians of the child to assist with the cost of making private transport arrangements. A transport grant is paid

- if the child has to be brought to a specific pick- up point to meet a special transport service

- if the child requires a supervised transport service and it is not possible to provide this service
- if there is no special transport service available for a child with special needs travelling home from a residential school at the weekend.

The rate of grant payable depends on the mileage involved and the amount paid is subject to school attendance. The transport grant can be appealed in individual exceptional circumstances to facilitate transport arrangements. Such appeals can be made in cases where

- the Department is not in apposition to provided a transport service due to excessive cost
- where the maximum level of grant offered does not cover the assessed cost of the journey involved
- following investigation of an appeal, the Department is satisfied that the child's parents/guardian are not in a position to transport the child, or that the circumstances of the family are such that hardship would be involved by requiring the family to pay for private transport.

Where appeals are found to be cases of genuine hardship, special services or enhanced grants can be arranged.

Submissions to the Task Force suggest that the current provision of transport is problematic. At present there is evidence to suggest that some children with ASDs have to rely on an unsatisfactory transport system to convey them long distances to special schools or to designated mainstream settings, **others do not have transport provision.** The unsatisfactory nature of the current arrangements can lead in some cases to problems such as unmanageable and dangerous behaviour on either buses or taxis. As part of an initial response to this problem it will be necessary to ensure that an adequate provision of transport escorts is put in place **for those students with ASDs for whom personal safety is an issue.** However, for a number of possible reasons, transport escorts are difficult to acquire. These reasons may include the nature of the job, general conditions and demands of the work and the level of pay. The Task Force believes that the Department of Education and Science should establish its own transport service for all students with special needs, as required and with respect to the individual students' needs. This would involve the employment of full time drivers and escorts leading to the provision of safe and timely transport to and from school for those children with ASDs who are in need of this level of support. It should also be noted that the current practice of offering a grant to families, although inadequate in cases **where the student with an ASD may have an additional learning disability/ behavioural challenges, this option may meet the needs of the more able students with ASDs in mainstream classes.** Finally, it has to be remembered also that transport is needed not only at morning and evening but also during the school day, in the majority of cases, to facilitate the implementation of important in-community educational programmes.

School transport is a sensitive issue for many students with AS/HFA in mainstream classes. The importance of maintaining confidentiality regarding disability status among peers, the efforts of this group to 'fit in' with

mainstream peers and the difficulties relating to bullying, victimization and peer rejection have been highlighted throughout this report. Clearly, the option of a school bus and an escort would not meet the needs of such students due to the potential of such a transport service to isolate and further stigmatise. It is critical that students with AS/HFA in mainstream inclusive classes are provided with practical and discreetly arranged transport provision. Submissions echo the findings of the research literature, which states that most bullying incidents occur during unstructured hours, and while coming to, and going from school. Protection from victimisation is a serious issue for this group. Taxi transport or the availability of the transport grant should be extended to the families of AS/HFA students in mainstream schools who may be experiencing difficulties of this nature and therefore may be unable to use the regular transport system. An Information Leaflet on transport entitlements for students with special needs across the range of educational settings should be issued by the Department of Education and Science and should readily available to parents through the mainstream and special schools schools.

8.6.6 Advice, Support and Quality Assurance

The Task Force is aware of the necessity for advice and support for teachers involved in the education of children with ASDs. The Visiting Teacher Service for ASDs, proposed in Chapter 5, could be a valuable source of information, advice and support to teachers of children with ASDs, right across the different educational settings. This service would be of particular importance to teachers of children with ASDs in mainstream settings.

There is also a need for regular monitoring of the quality of educational provision for children with ASDs. The Department of Education and Science Inspectorate have always had that important quality assurance role. Therefore, the Task Force recommends that the Department of Education and Science Inspectorate regulates and annually reports on primary provision for children with ASDs across the range of settings.

8.6.8 Research

Research specific to the primary-aged child within the Irish context is needed both to provide basic data and to evaluate different models of provision and curriculum and to inform current and future practice

8.7 CONCLUSION

The review, by the Task Force on Autism, of primary education provision for children with ASDs shows that there are many problems and deficiencies. The Task Force recommends that a range of differentiated provision, suitable to the varying needs of pupils across the spectrum be made available. This must be sufficient to meet the demands, across the geographical regions, and should be based on age, ability, disorder-appropriateness and parental choice. It must be accompanied by appropriate and sufficient services and must be made in the

context of effective school planning. Curriculum must be disorder- and ability-appropriate and Individual Educational Plans must be available for all children with ASDs.

8.8 Recommendations

The Task Force recommends:

- 1.* that provision for children with ASDs be sufficient to meet demand in all geographical regions and be based on admission criteria which reflect diagnostic category, assessed needs and parental choice;
- 2.* that the function of 'special needs co-ordinator' be assigned to a named teacher in each school;
- 3.* that provision for children with ASDs ensure appropriate opportunities for meaningful integration/inclusion with their similarly aged peers and be written into the school plan;
- 4.* that the Department of Education and Science secures sufficient support services for children with ASDs;
- 5.* that Special Needs Assistants be adequately trained and remunerated;
- 6.* that a review of the progress and the Individual Education Plan for each child with an ASD be carried out annually or at the appropriate request of a parent or teacher;
- 7.* that there be a full, independent, multi-disciplinary assessment to effect the smooth transfer of the children from the primary sector to the second level sector;
- 8.* that children with ASDs in primary schools have full access to the curriculum of their similarly aged and ability peers, with appropriate modification, as identified by the relevant Statement of Need and Individual Education Plan;
- 9.* that pupil/teacher ratios should continue to remain small, as for early education, and responsive to individual needs;
- 10.* that the Department of Education and Science inspectorate regulates and annually reports on primary provision for children with ASDs;
- 12.* that schools review, at least annually and in the context of the school plan, their provision for children with ASDs in order to inform practice and make improvements.
- 13.* that schools actively support and involve parents of a child with an ASD in all aspects of the education of their child;

14. that schools facilitate and encourage staff to undertake continuing in-career development in order to respond effectively to the needs of children with ASDs.
15. that enrolment in classes for children with AS/HFA will be based on average intellectual ability and cognitive functioning in accordance with DSM IV diagnostic criteria for Asperger syndrome;.
16. that An Information Leaflet on transport entitlements for students with special needs across the range of educational settings be issued by the Department of Education and Science; that this leaflet be easily accessible and readily available to parents through the mainstream and special schools schools.

CHAPTER 9

SECOND LEVEL EDUCATION: ASSESSMENT, PROVISION, CURRICULUM, TEACHING METHODS AND SUPPORT SERVICES

This chapter will review the current status and inadequacies of the educational service provision for second level school-aged pupils with an ASD in Ireland. It will outline what the Task Force on Autism perceives as good practice for this category, based on the multitude of submissions received and additional information accessed over the course of the Task Force's work. Finally, recommendations will be made to begin addressing the multitude of needs identified for this age level.

9.1 CURRENT PROVISION

9.1.1 Educational Provision

The main settings for pupils of post primary age at present are as follows:

- One Special School for pupils with ASDs, who also have Moderate to Severe general learning difficulties, (Setanta NS, Beechpark, Stillorgan, Co. Dublin);
- Special Classes for pupils with ASDs in Special National Schools for pupils with Mild and Moderate general learning difficulties;
- A number of pupils with ASDs have been placed in Special Schools for other categories including Special Schools which primarily cater for:

Mild General Learning Difficulties
Moderate General Learning Difficulties
Severe/Profound Learning Difficulties
Emotional and Behavioural Disorders
Multiple Disabilities

- Mainstream settings with Resource Teacher support;
- Home Tuition.

9.2 REVIEW OF CURRENT PROVISION/CONCERNS AND INADEQUACIES

9.2.1 Entitlement to Educational Support

It is noteworthy that while all pupils with disabilities within the primary school system now have an automatic entitlement to a response to their needs as per Circular 8/99, this automatic entitlement has not yet been extended to pupils at the post primary stage. In practice, however, provision is made for all identified post primary pupils with disabilities at the request of the school. However, evidence from submissions indicate that considerable delays in procuring this provision, are, in many instances, the norm. Submissions have also stressed the importance of any allocated resources for a pupil with ASDs being ring-fenced for the pupil in question.

9.2.2 Range of issues raised in submissions

Issues relating to second level education were raised in twenty submissions. The submissions mainly concerned the difficulties young people with ASD experience at second level, the gaps and absence of provision and the kind of provision needed, and the support services needed by students and schools. There was a particular focus on young people with Asperger's Syndrome in the submissions received. In particular, concern was expressed about the number of unidentified pupils with AS/HFA, who may be in mainstream provision at present without support, or out of school altogether.

9.2.3 Inadequacy of present provision

It is evident that the current provision for pupils with ASDs at second level is very limited, both in range and extent. The inadequacy of second level provision was raised in a number of submissions, and there is clearly considerable concern among parents regarding the eventual placement of pupils, who are now under twelve years of age. The parents of pupils who will be of post-primary age in the near future are particularly anxious regarding future educational arrangements. These concerns were also evident during the visits of Task Force members to various primary school settings. One contributor encapsulated the general anxiety among parents by asking:

What will happen to pupils in special classes in mainstream schools when they reach 9 years of age? Will the principal and Board of management require them to leave? This is a very real issue for a number of our parents whose pupils are nearing this age.

Similarly, the parents of a boy who is suitably placed at present in a special unit in a mainstream primary school informed us that:

...the battle continues in that he is due to enter secondary school next September and as yet no facility is in place to cater for his need and entitlement under our constitution for an education. We sincerely hope that the Task Force will highlight the appalling lack of services to these pupils and their parents.

There are serious concerns regarding the difficulties encountered in procuring the placement of students with ASDs within mainstream classes, or in establishing special classes within mainstream schools.

9.2.4 Continuum of Provision

The submissions stress that the same flexible continuum of options that is needed at primary level is essential also at post-primary level. One detailed submission included a comprehensive set of recommendations on post-primary and pre-vocational provision. These recommendations propose a similar continuum of provision, statementing, review and Individual Education Planning procedures as are available at primary level.

Concern regarding lack of provision and inadequacy of mainstream support at secondary level for young people with Asperger's Syndrome is a particular feature of many submissions. Many of these young people could expect to be accommodated in mainstream post primary provision, as appropriate, but current practice is not uniform.

Adolescents with AS/HFA, who cannot cope in mainstream schools, are at a particular disadvantage as they do not fit appropriately into existing categories of special education/health provision. They are often referred to services where their particular needs are undiagnosed or unmet as there are few, if any, AS/HFA specific initiatives available outside the Eastern Regional Health Authority (ERHA). Students with AS/HFA are therefore frequently misplaced and marginalised as a result.

The report of a working group on Asperger's Syndrome (SWAHB, 2001) captures the difficulties associated with placement of this group in the following extract:

There is a real paradox when providing for the education of persons with AS/ HFA. Most of the learning difficulties of persons with AS/HFA result from the social interaction and communication problems, which would seem to rule out mainstream education. Yet learning for them in social and life skills can only take place by mixing with normal peers during the educational process. Thus while a case can be made for many handicapped, which in the past

have been placed in special schools to be integrated into mainstream education to their own benefit, in the case of persons with AS/HFA inclusion in mainstream education is a must if the social skills deficit is to be addressed. :(SWAHHB, 2001. p 15)

9.2.5 Transition Difficulties

Some submissions focused on the problems of transition from primary to post-primary schooling. One parent wrote that:

The confusion of a secondary school will only lead to more anxiety/depression, which in turn will have a detrimental effect on his behaviour. It is my biggest fear that he will one day end his own life.

A Consultant Child and Adolescent Psychiatrist drew attention to the stress students can experience at second level because of insufficient supports. This contributor pointed to “*a huge gap between primary and secondary provision*”, and also drew attention to issues of bullying, peer pressure, underachievement, and co-morbidity with problems such as ADHD, anxiety and depression.

9.2.6 Support Services

The range of support services needed by students at second level was identified in a number of submissions. These include classroom assistants, resource teaching, appropriate teaching materials, ongoing assessment, review, statements of needs, multidisciplinary support services and teachers who are trained to address the needs of students with ASDs.

The submissions highlight a number of key features of second level schools, which pose difficulties for students with AS/HFA. These focus on a combination of school organisational issues such as changes of teachers, subjects and class locations, and on the social integration difficulties routinely experienced by students with AS/HFA. Difficulties in coping with examinations were also mentioned. At present school staff do not feel adequately skilled to cope with pupils with AS/HFA either in terms of pre-service training or ongoing continuing professional development (CPD). There is a shortage of information regarding mainstream classroom strategies, which can accommodate the learning styles of students with AS/HFA.

Furthermore, staff may frequently overlook the extent of impairment present in people with AS/HFA. Teachers may have limited knowledge and experience of the difficulties encountered by people who appear 'able', despite having developmental disorders. These students need a school environment where their teachers appreciate their difficulties and are trained in educating students with the significant social/communication deficits, which characterise their condition.

The submissions also highlight the need for close co-ordination between State Departments in order to facilitate the provision of comprehensive and integrated service delivery to students with ASDs at post primary level.

9.2.7 Curriculum

It is very important that the curricular needs of pupils with ASDs at post primary level in special and mainstream school settings are identified and appropriately addressed. Particular attention should be paid to developing or adapting a curriculum for each individual with autistic spectrum disorder. The curriculum should be based on long-term goals and should incorporate strategies designed to assist with access to life long learning in the form of continuing education, vocational training and/or third level education. Students with autistic spectrum disorders may have difficulties in the social skills area and show an inflexibility of mind, which can create severe difficulties for them in accessing training and employment opportunities. The curriculum at second level, therefore, must attempt to remediate and minimise these difficulties. The submissions recommend that pupils with an ASD should be able to avail of alternative curriculum initiatives and modes of assessment.

The curriculum needs to be considered from the perspectives of both pupils attending mainstream post primary schools and pupils advancing to the Senior Department of Special Schools. It is to be expected that the vast majority of pupils in mainstream post primary settings will be within the AS/HFA category. Special schools cater for pupils up to 18 years of age. They are recognised as national schools and are therefore part of the primary school system. There is no prescribed curriculum for this category although the NCCA is currently charged with preparing curriculum guidelines for pupils with general learning disabilities. The need for an appropriate second level curriculum for this category has been stressed in a number of submissions.

9.2.8 Identification of pupils with Asperger's Syndrome/High Functioning Autism (AS/HFA)

As evidenced elsewhere in this report, the number of diagnosed cases of Asperger's Syndrome is nowhere near the predicted level of incidence (see Chapter 2). A number of submissions refer to the lack of prevalence studies in this country. One contributor pointed out that:

Work in other countries has indicated that the level of Asperger Syndrome may be at least 6 times the level of classic autism. The condition is much more common among males than females by a ratio of about 7:1.

A report of a survey of pupils with Asperger's Syndrome in primary and secondary schools in Northern Ireland commented that '*present numbers appear to be significantly underestimated in the Province as a whole*' (Department of Education (Northern Ireland) 2001, p.3)

Late diagnosis of AS/HFA continues to pose significant difficulties for students at second level stage. One submission from a group of parents informed the Task Force that:

Many of our pupils were not diagnosed as having Asperger Syndrome until the pupils had spent years in special schools or mainstream schools. Very often the formative years had passed without diagnosis due to lack of resources or downright failure by the existing structures to recognise and discuss the problem. Early diagnosis is vital.

Although early assessment and diagnosis are vitally important and desirable, it is equally important to acknowledge that persons with AS/HFA also routinely present for diagnosis during adolescence and adulthood. Indeed a number of submissions refer to inappropriate placement of young adults with AS/HFA in psychiatric hospitals or other institutions.

9.3 Models of Good Practice

Members of the Task Force visited three special schools in England, which cater for pupils with ASDs of post primary age.

The features of post primary provision which impressed members arising from these visits were the following:

- Autistic Diagnostic Unit/Training Centre attached to school;
- Promotion of school as a regional centre of excellence with outreach services radiating from centre;
- Family Support Worker seen as key member of staff;
- Availability of respite care;
- Flexible Pupil-Teacher ratios;
- Non-contact teaching time made available for Class Teachers;
- Individual education plans linked to National Curriculum;
- Good record-keeping and regular monitoring of school progress including academic and developmental profiles and checklists;
- Annual reviews involving pupils, parents, school staff and educational psychologist;
- Visits to school by Consultant Psychiatrist;
- Therapy provided by Health Authority;

- Workshops for Parents on behaviour management and other topics;
- Transition Programmes available leading to third level placement/supported employment;
- Transition Review at 14+ involving multi-disciplinary assessment;
- Further Education Unit part of school provision with links to local FE College;
- Behaviour support team in school to address challenging behaviour.

It should be noted that while some of the above features would be considered specific to special provision, others could be incorporated in mainstream settings.

9.4 Continuum of Provision

It is the view of the Task Force that there should be a flexible range of educational models in relation to post primary provision for pupils with autistic spectrum disorders. The Task Force on Autism considers that the range of options for pupils with autistic disorder might include the following models of provision:

9.4.1 Options For Provision

- Full-time placement in a mainstream setting with necessary supports, e.g.. supported by Resource Teacher as appropriate;
- Placement in a special autistic disorder class with integration for agreed activities/classes;
- Part-time placement in a special autistic disorder class in a mainstream school, i.e. supported integration in mainstream classes for agreed activities/classes;
- Full-time placement in a special class for pupils with autistic disorder in a mainstream school;
- Placement in a special school for autistic disorder;
- Class for pupils with autistic disorder and an intellectual disability in a special school (with autism support);
- Placement for pupils with autistic disorder and an intellectual disability in a special school for intellectual disability (with autism support);
- Residential special schools for autistic disorder pupils with significant behavioural needs and/or lower levels of intellectual ability.

9.4.2 ‘Least Restrictive Environment’

The ‘least restrictive environment’ philosophy is supported by the Task Force, with the recognition that a segregated school environment may be appropriate for some pupils at times. Any recommendation regarding the placement of a pupil with an ASD should be made on the basis of a multi-disciplinary assessment (as discussed below) and have regard to the desirability of local provision. The Task Force wishes to emphasise that some of the above models are more appropriate for pupils with autistic disorder, while others are more appropriate for students with AS/HFA. This matter is further discussed in the next section.

9.4.3 Differentiated Models of Provision

The Task Force considers that there is a need for a range of differentiated models of provision for ASD in respect of the two categories of classic autism and AS/HFA. It is recognised that people with AS/HFA require a different service to those with autistic disorder, and that the availability of designated autism specific provision should not, therefore, be seen as the ideal placement option for all pupils with ASDs.

While some students with AS/HFA will be appropriately placed in mainstream post primary provision with additional supports and others will be placed in specialist settings, it is likely that all will require additional curricular and personal supports in both across the range of settings. It is important that to note that placement of students with AS/HFA in schools for pupils with emotional disturbances is not a desirable option (Atwood, 2000; Klin & Volkmar, 2000). In many cases such a placement has tended to exacerbate the difficulties of students with AS/HFA. The Task Force is also aware that the majority of parents are vehemently opposed to challenging behaviour units for the *management* of pupils and young adults with AS/ HFA.

Provision options for this category should seek to ensure equality of opportunity for all students with AS/HFA throughout Ireland. In the case of pupils with AS/HFA it is considered that the following range of placements would be appropriate:

- full time placement in mainstream post primary classes with adequate level of support;
- part-time placement in a special class for pupils with AS/HFA in a mainstream school, i.e. supported integration in mainstream classes for agreed activities/classes;
- full time placement in an age-appropriate special class for AS/HFA students in mainstream second level school with additional supports as appropriate;

- home tuition;
- Residential AS/HFA specific school for a minority of adolescents.

It will be noted that the above models range from inclusive mainstream settings to highly supported residential settings . Special settings would ideally be regional resource centres radiating outwards to support students with AS/HFA in other educational settings as appropriate. The Task Force recommends that any additional resources allocated to a pupil with an ASD should be ring-fenced in respect of that pupil.

9.4.4 Evaluation of Provision

The Task Force believes that that the effectiveness of provision for students with ASDs in second level schools be regularly monitored and annually reported on by the Department of Education and Science Inspectorate. The feedback and views of parents and, to the extent possible, students, should be included in the evaluation process.

9.5 ARRANGEMENTS FOR SECOND LEVEL PLACEMENT

The Task Force considers it unacceptable that parents should be required to access the second level system on their own, with all the consequent scope for mutual anxieties and misunderstandings arising on the part of parents and school staffs. Second level placement for pupils in mainstream provision, or in autism or AS/HFA classes attached to mainstream schools, should be arranged prior to transfer from the first level setting, following an updated multidisciplinary assessment. The placement of pupils in special schools should be similarly reviewed and the most appropriate placement arranged.

As recommended in Chapter 8, the Task Force considers that a full multi-disciplinary assessment should be carried out on each child with an ASD prior to completion of the primary stage. It is recommended that this assessment should take place not later than January of their final year in primary school.

Following this assessment, the Special Needs Organiser (SNO), or appropriate Department of Education and Science officer, should have the responsibility, with parental agreement, for identifying and securing an appropriate post-primary placement for students with ASDs. The SNO or officer should then effect the negotiation of the appropriate transfer arrangements, in consultation with the parents.

It is important that the criteria for admission of students with AS/HFA in second level schools should be clearly stated, readily available, and communicated to the parents of all prospective pupils. Strategies should be identified to ensure equality of access to mainstream schools with opportunities for full participation and

inclusion. Enrolment in post primary special AS/HFA classes for children with AS/HFA should be based on cognitive functioning in the average range in accordance with DSM IV diagnostic criteria for Asperger syndrome. Methodologies, which accommodate the particular learning style of this group and also facilitate the appropriate delivery of the national curriculum, need to be identified.

Appropriate members of staff of the receiving school should also participate in the process of updating the child's individual education plan. This will ensure that realistic targets can be set.

As mentioned in Chapter 8, it is particularly important that the entitlements/supports attached to each child are, subject to appropriate modification, automatically transferred to the next educational setting, and that the new school authorities are not required to apply for resources *ab initio*.

Following transfer from primary school, the secondary school staff will have responsibility for monitoring the child's IEP and making periodic appropriate adjustments. The professionals involved with the child should assist in this process and recommend additional educational resources where this is deemed appropriate and at the request of parents.

9.6 CURRICULUM

9.6.1 Access to Appropriate Curriculum

The overriding consideration in regard to the curriculum at post primary age level is that pupils with an ASD should have access, to the extent possible, to the same curriculum as their peers, while also having access to a curriculum appropriate to their specific needs. This should be the case whether the pupil is attending a mainstream second level school or is in some form of special provision. The Task Force recommends, therefore, that all post primary students with an ASD should have access to the most appropriate curriculum and accreditation route to match their ability and direction.

9.6.2 Range of Curricular Provision

Students with an ASD should have the opportunity of participating to the extent possible in the standard post primary curriculum or availing of alternative programmes such as the Junior Certificate School Programme and Leaving Certificate Applied Programme, where appropriate. Although some AS/HFA students have the ability to participate in the standard mainstream Junior and Leaving Certificate examinations, others may need to avail of the Junior Certificate Schools Programme (JCSP) which includes individualised school-

based assessment as well as State certification. The JCSP Programme adopts a student-centred approach to the Junior Certificate specifically aimed at those young people who show signs of school failure or early leaving. The Leaving Certificate Applied employs a modular approach to curricular content and includes assessment of communication, problem solving, practical and interpersonal skills.

The National Foundation Certificate programme may be appropriate for some students with an ASD. This is a foundation level programme operating under the aegis of the former National Council for Vocational Awards (NCVA) which has recently been subsumed under a new body, the Further Education and Training Awards Council (FETAC) (see Chapter 14 and Appendix 18). To achieve certification level a student must successfully complete eight modules, including three core modules in communications, mathematics, and personal and interpersonal skills.

The students who can participate in the programmes described above will mainly fall within the AS/HFA category. Special consideration, therefore, need to be given to addressing the curricular needs of students with ASDs whose needs are not met by the above programmes.

Special National Schools should particularly acknowledge the dignity and self-esteem of senior students so that they are aware of their enhanced status in the school. Their transfer to the Senior Department should be marked by a rite of passage involving a formal transition to a new curriculum, which is tailored to their special skills and interests and delivered by subject teachers where necessary, and formalised in a new Individual Education Plan.

The National Council for Curriculum and Assessment (NCCA) is currently developing guidelines for students with general learning disabilities in second level settings, ranging from severe/profound to mild. These guidelines will emphasise a student-centred approach, flexibility in teaching approaches, active learning, use of concrete materials and real life problem solving. Communication and language, and Social and Personal Health Education (SPHE) will feature as key curriculum areas, as well as a partnership approach to education. These guidelines should be helpful in making appropriate curricular provision for lower functioning students with an ASD.

9.6.3 Curriculum Content for Pupils with ASDs

For all pupils with ASDs second level provision should take a 'whole person' view and have the flexibility to facilitate more than just 'classroom studies'.

The following topics should be covered in all post-primary educational settings:

- Living skills
- Independent Living Skills
- Social skills
- Family and community life
- The world of work
- Individual development
- Sexuality
- Cognitive skills
- Coping with isolation, loneliness and peer rejection
- Coping with the social pressures of adolescence
- Coping with all the changes of teachers, subjects and classrooms
- Coping with unstructured time, i.e. break-time, free classes and lunch time
- Maintaining a level of self-esteem
- Maximisation of talents and practical skills

In addition the following areas need to be addressed for pupils with AS/HFA:

- Recognition that people with AS/HFA have positive attributes which could be tapped to promote 'inclusion' within schools
- Coming to terms with the implications of AS/HFA

Information and Communications Technology (ICT) can be employed to assist pupils with ASDs to acquire a range of skills including literacy and numeracy skills. Two recent publications offer useful guidelines to teachers on the use of ICT with various disability categories.

- (i) *Special Educational Needs and Information and Communications Technology: Information and Advice*. National Centre for Technology in Education (NCTE). November 2000.
- (ii) *Enabling Technologies. Guidelines for the use of Assistive Technology in Education*. Bradshaw Books. 2001.

ScoilNet, the website for Irish schools, has a special needs section which includes material on autism.

The merits of ICT as a means of bridging the communication gap experienced by the group with AS/HFA should be investigated. Many students with AS/HFA are visual learners and routinely under-achieve due to the mismatch between traditional methods of teaching and their special needs. The provision of computers for individual students would, therefore, be of enormous benefit in

enhancing opportunities for learning without the constant stress of social interaction and peer pressure.

9.6.4 Issues relating to students with AS/HFA

The option of studying for the minimum six subjects only at state examinations would facilitate the inclusion of therapeutic support and the development of social understanding and communication skills within the adapted curriculum. The implementation of an appropriately designed social, communication and life skills second level subject would be of significant value to students with AS/HFA. Students could take this subject in mainstream class on an individual basis with the assistance and guidance of the appropriately trained resource teacher or as part of the adapted curriculum in special classes/schools. This measure, if appropriately designed, implemented and delivered, would have unprecedented potential for long term positive outcome in the lives of people with AS/HFA.

Students with AS/HFA should be integrated into mainstreamed classes for subjects that interest them and are related to their strengths. Traditionally, students with general learning disabilities are integrated for subjects such as physical education classes. This strategy is likely to be far less successful for pupils with AS/HFA, who find it difficult to cope with the social orientation and lack of structure which characterise such classes. Experience shows that they are more successfully integrated into structured classes, which are related to their academic strengths and interests, such as computers, geography, biology, and mathematics.

Academic success can be facilitated in many instances with students with AS/HFA through gearing curricular assignments to their special interests. Where classes rely on 'verbal' teaching, the student with AS/HFA will need assistance in note taking. In this situation, the teacher might provide them with an outline of the lesson, which highlights the key points of the lesson.

9.7 REASONABLE ACCOMMODATIONS IN CERTIFICATE EXAMINATIONS (RACE)

A number of submissions referred to the difficulties that students with AS/HFA experience during the state examinations. The NEPS psychologist will have a particular responsibility for ensuring that, if appropriate, special arrangements are in place for any child sitting for the State Examinations.

Individuals with autistic spectrum disorders (and indeed other disabilities) who are disadvantaged as a result of their impairments may need reasonable accommodations in Certificate Examinations. Special arrangements are designed to remove, as far as possible, the impact of a disability on a candidate's

performance, so that he or she can demonstrate in the examination his or her level of achievement. The special arrangements include, assistance from a scribe or reader, use of a word processor or tape-recorder, or accommodation in a special centre. A candidate may also be eligible for exemption from the spelling and grammatical components in language subjects and extra time to complete written examinations.

The current DES guidelines issued to schools in relation to reasonable accommodations for examination students state that:

When an element or elements of an examination have been waived, so that the purpose of the examination regarding that element or elements has not been met, or the method of examining has been significantly altered, this should be indicated by the presence of an explanatory note on the candidate's certificate of results.

This is listed as Principle No. 12 of 'Principles on which the provision of arrangements for candidates with special needs are based' (and is derived from the Report of the Expert Advisory Group on Examinations, January 2000) in the following document (which bears no reference number): *Guidelines for Schools in relation to completion of Application Forms for Candidates sitting the Junior Certificate Examination in 2001.*

The Task Force is aware that this aspect of the RACE arrangements is proving very controversial with the parents of pupils with ASDs and other students with disabilities and, indeed, with the students themselves. The accommodations are seen as equalising opportunities to demonstrate the level of knowledge gained in a particular area. It is felt that the method of relaying the depth of learned information and understanding is unimportant as the purpose of exams is to ascertain the level of information and understanding attained in a given subject.

The 'flagging of results' reduces the value of the results achieved and undermines their status. Furthermore, prospects for entry to college, training and further education and employment may be adversely affected by the perception that the validity of the results is questionable. Flagging would appear to violate notions of privacy as well as equality. It is strongly felt by many that the goal of affording reasonable accommodations, which is to achieve a level playing field for all students, is undermined by the 'flagging' of the examination results. The Task Force, therefore, recommends that the DES urgently reviews the practice of attaching explanatory notes to the candidate's certificate of results.

9.8 SUPPORT SERVICES

9.8.1 Range of Support Services

A number of submissions outline the range of educational, social and therapeutic support services required to enable pupils with ASDs to make maximum progress at second level. These include access to professionals such as speech therapists, occupational therapists and psychologists, resource teaching by appropriately qualified personnel, visiting teachers, classroom assistants, appropriate teaching materials and methodologies, adequate Information and Communication Technology (ICT) supports, counselling, social integration supports and career guidance. The National Educational Psychological Service (NEPS) and the proposed National Education Welfare Service should also have a role in helping persons with ASDs.

The Task Force considers that the following range of support services should be available to all students with ASDs as required:

- Resource teachers
- Classroom assistants
- Visiting Teachers
- Befriending initiatives
- Social skills/understanding groups
- Bus/taxi transport facilities
- Speech & language therapy
- Occupational therapy
- Clinical and educational psychological services (including counselling)
- Family support/counselling
- Partnership Facilitator Scheme (see Chapter 3)
- Appropriate training in the use of ICT
- Provision of computers

The extent to which these services are available at present varies considerably across the country, with in some instances minimal or no access to some services being the norm. The Task Force considers that support services should be fully accessible to all pupils with ASDs, regardless of whether their educational placement is in home-based, mainstream or specialised settings.

The following additional support services are required for students with AS/HFA at second level:

- Strategies to accommodate the need for routine;
- An arrangement whereby 'notes' used by teachers can be photocopied for students;
- Protection from bullying;
- Strategies to promote social inclusion;
- Mentor systems and befriending/buddy schemes;

- Social skills groups/classes during school day and also during vacation periods;
- Provision of paid advocates to facilitate inclusion in leisure and community activities;
- Special career guidance counselling.

The following extract from the Department of Education survey in Northern Ireland identified a number of key features of good school practice in making appropriate provision for Asperger's Syndrome students:

A significant finding of the survey was that the pupils were more at ease in a school setting where their needs were considered at whole-school level, and the staff had an agreed set of strategies to encourage the pupil to interact positively with their teachers and peers, and to seek assistance when needed. Another significant factor, which contributed to good practice, was the importance of a consistent teaching approach and a highly structured environment of routines, particularly for the younger pupils. (Department of Education (Northern Ireland) 2001, pp.8-9)

9.8.2 Support in School

Befriending schemes and peer groups for social integration and the development of social skills would be beneficial for many pupils/adolescents with an ASD. Such schemes should be undertaken with caution and expert advice in recognition of the potential difficulties that could arise through failure, and all befriending should be arranged only with the clear agreement of parents and the person with an ASD. Appropriately trained professionals could again advise on the facilitation and development of these groups and schemes.

Students with ASDs might also benefit from having an assigned buddy who accompanies him/her in some less structured social situations. Such buddies might also help the student to develop leisure skills, opportunities to interact with peers, etc. College students are often willing to 'mentor' or help adolescents by accompanying them on a community outing each week to places such as coffee shops, restaurants, the cinema, or the gym. This mentoring approach is often particularly effective for students with AS/HFA in terms of imparting social skills. It also complements instruction from parents and teachers.

It is also important that schools and parents should have access to information, guidance, training and the advice of 'an expert group' appointed by the Department of Education and Science.

9.8.3 Speech and Language Therapy

The vital input of speech and language therapists in the development of pupils with ASDs is fully recognised. A submission from a Speech and Language therapist has pointed out that persons with AS/HFA often fail to understand the intentions and viewpoints of others, have literal interpretation because of pragmatic and conceptual language and difficulty with metaphors, sarcasm and humour. It is important that school staffs should be aware of these characteristics and deficits and adapt their language usage accordingly.

9.8.4 Role of Educational Psychologist

NEPS (The National Educational Psychological Service) is moving towards a situation where each NEPS psychologist will be covering a number of second level schools together with the appropriate feeder primary schools. This development will lead to a more cohesive and integrated model of service delivery, which will eventually ensure continuity of services for the pupils involved. The same NEPS psychologist can therefore continue to be involved with pupils with ASDs throughout their school careers.

Many pupils/adolescents with ASDs are deeply troubled by their social ineptitude, their lack of social acceptance by peers, and their isolation and rejection. The educational system should therefore be sensitive to the individual student's age and level of awareness. In particular school strategies and support structures need to be put in place immediately for all students, and particularly for those with an ASD, who are currently enrolled at second level. The NEPS psychologist will have a role in advising on appropriate strategies to maximise the child's inclusion in the social life of the school.

The NEPS psychologist will also have a key role in ensuring that the child settles in well and that the recommended learning and counselling supports are provided and adequate. Liaison with the guidance counsellor and learning support members of staff will be of particular importance in this regard.

In addition, the NEPS psychologist will have a general monitoring role, which will include, in consultation with the teachers, parents and other professionals involved, advising on adjustments to the child's individualised education plan. The child should be involved in this process to the extent possible. Additional educational resources will be recommended where this is deemed appropriate.

The NEPS psychologist will work collaboratively with the teachers, Special Needs Assistants, parents and other professionals to support the child throughout the post primary placement. This work may include contributing to in-service support for staff members and parents. It is important that all members of staff are included in any such in-service provision, and that they are made aware of, and sensitive to, the specific and differing needs of pupils with ASDs. This consideration is of considerable importance at the post-primary school because of

the large number of staff coming into contact with any given child. One unscheduled encounter with an uninformed member of staff could have far-reaching implications.

9.8.5 Counselling

Individual and/or group counselling will be necessary for persons with AS/HFA, particularly concerning difficulties in the area of social interaction. This should be provided by psychologists in mainstream school settings. The guidance counsellor and pastoral care staff, who should be enabled to acquire the necessary training for this sensitive role, should provide counselling in mainstream school settings. The students should have access to whatever counselling support is deemed appropriate from the NEPS psychologist working in collaboration with the relevant clinical or counselling psychologist. It is advisable that students will also have access to counselling services, which can be provided or arranged by the new Health Board regional ASD Intervention Services.

9.8.6 Visiting Teacher Service

The Task Force considers that the Visiting Teacher Service for ASDs (proposed in Chapter 5 of this Report) will continue to play an important function in supporting pupils with ASDs at second level. The Visiting Teacher will have a particularly important role in ensuring continuity in the education of the student with an ASD as she/he makes the transition between different levels of the school system, especially in mainstream settings. The Visiting Teacher for ASDs will also be a source of advice and support for teachers.

9.8.7 Support for Parents/Families

As outlined elsewhere in this Report, the Task Force considers that all people with ASDs and their families should have access to a range of family support services, which can be provided by agencies of the Department of Health and Children. These services should include counselling, therapy, appropriate respite options, opportunities to network with other families, sibling support services, and information regarding entitlements, dietary interventions and current research findings on educational approaches. The provision of a help-line for parents should also be considered.

At school level the establishment of parent support networks should be encouraged and continued throughout second level education. Parent workshops and the availability of videos, information pamphlets and other literature should be facilitated. The Partnership Facilitator scheme (proposed in Chapter 3 of this Report) will play a crucial role in facilitating home-school partnership.

9.9 LIAISON ISSUES

9.9.1 Liaison between Education and Health

The submissions highlighted the need for close co-ordination between State Departments in order to facilitate the provision of comprehensive and integrated service delivery for students with ASDs at post primary level. As emphasised throughout the Report, links between the Departments of Education and Science and Health and Children need to be developed and strengthened. Liaison contacts and formalised protocols and procedures between key professional and administrative staff in the two Departments are of the utmost importance. The establishment and development of liaison structures at regional/local level will of equal importance.

9.9.2 Liaison between NEPS and the Health Board Psychological Services

Liaison between the National Educational Psychological Service (NEPS) and the clinical services, which operate under the aegis of the Health Boards, will be facilitated by the fact that NEPS is organised in Regions corresponding to the ten Health Board areas. It is envisaged that, subject to staff availability, a NEPS psychologist in each Region will have a specialism in the autism area. This colleague will act as a general resource person to the NEPS psychologists working in the Regions, and will also be the main link person with the relevant Health Board services and will liaise with the proposed Special Needs Officers (SNOs).

The ‘specialist’ psychologist will not, however, directly deal with all the pupils with ASDs in the area. In each individual case this will be the responsibility of the relevant NEPS school psychologist, who can of course access the support of the ‘specialist’ colleague as appropriate. It is important to stress that the intensive involvement entailed in working with students with ASDs and other disability groups is not factored into the current NEPS Development Plan. There will need to be a significant increase in staffing levels, therefore, over and above the current target figures, if the NEPS psychologists are to have a meaningful role in working with pupils with ASDs and young people.

The NEPS psychologist will also need to maintain contact with the appropriate clinical psychologist and other relevant professionals to ensure clarity regarding their respective roles. This will ensure optimal delivery of supports to the child. Inter-professional liaison will be particularly necessary when any major review of the child is being carried out or when a possible change of educational provision is being considered. A decision regarding transfer to any alternative form of provision should only be made on the basis of a full multi-disciplinary review assessment involving the relevant NEPS psychologist.

9.9.3 Collaborative Work Practices

The submissions stressed the need for collaborative work practices between teachers, professionals and parents. The Task Force believes that there should be better liaison between teachers, health professionals and parents with regard to the needs of people with ASDs. Teachers, classroom assistants, parents, health care staff and psychologists should develop partnerships, which ensure continuity of approach in order to enhance the development of the social, emotional, educational and life skills of students with ASDs.

9.9.4 Home-School Partnership

The importance of home-school partnership was stressed in Chapter 3 and also discussed in Chapter 5. At the second level stage parents and schools would also benefit from a clear set of written guidelines which highlight the necessity of regular home/school liaison. It is important that the DES should issue and circulate written guidelines outlining the necessity of regular home/school liaison in respect of students with ASDs, and outlining the manner in which effective home/school liaison should take place. As suggested in Chapter 5, the Home School Community Liaison Scheme (HSCL) already established in areas of disadvantage could provide a helpful model for the development of closer co-operation between parents and teachers and it is the model for the proposal of Partnership Facilitator proposed in Chapter 5.

9.10 PLANNING FOR TRANSITION TO POST SECOND LEVEL PROVISION

9.10.1 Transition Plans

As with all educational transitions, considerable preparation will be required before the third level or continuing education stage to ensure a smooth and anxiety free transfer for students with ASDs. Transitional school to college programmes, will, in some cases need to be developed. Such transition programmes or plans are already in use in the USA & the UK. The education system has a duty to teach, inform, and encourage individuals with autistic spectrum disorders to take control of their lives to the maximum of their potential. Parents or professionals should not have the power to veto an informed decision made by a person with autistic spectrum disorder without adequate grounds.

The Task Force considers that preparation and planning for post second level education should be a basic component of the student's individual education plan (IEP), and should begin well in advance of the post second level placement and ideally during the second year of secondary school.

Planning the transition should be a collaborative process which involves the individual with an autistic spectrum disorder, parents, school staff representative, the NEPS representative, career guidance counsellor, and the proposed parent/school partnership facilitator (PF). It is expected that the local SNO, as proposed by the Report of the Planning Group entitled '*A National Support Service for Special Education for Students with Disability*' (DES, 2000), and a representative from the relevant ASD intervention service or Health Board will be key participants in this planning process.

Issues, which will need consideration in planning for third level and continuing education, include:

- Advocacy and maintenance of family relationships;
- The development of individual strengths and interests;
- Post secondary education/training options;
- Accommodation/residential options and support;
- Transportation needs;
- Income support opportunities;
- Counselling services;
- Community, leisure and recreation opportunities.

The curriculum at this stage should include modules that specifically strengthen those areas, which are often barriers to integration and successful employment:

- Interviewing skills
- Coping strategies/stress management
- Job retention skills
- Role and duties of employment/employee
- Relationships with co-workers
- Organising of non-working periods

9.10.2 Review of Transition Plan

A formal review of the post second level transition plan should take place at approximately fourteen years of age or not later than the end of the Junior Cycle stage. This review should automatically update the IEP, and take account of the educational and vocational life-plan of the student. At this stage it will be important to prioritise subjects that prepare students across the whole autism spectrum for independent living, and special subjects (taught by Subject Teachers) should be carefully selected to suit the individual child.

9.10.3 Assessment for Transition to Post Secondary Education

An independent comprehensive multi-disciplinary transition assessment will need to be carried out in order to identify appropriate continuing education placements, third level education placements, and vocational options. This should take place during the final year of second level education (at whatever age this occurs). The Special Needs Organiser should have responsibility for ensuring that the transition assessment takes place.

Post-secondary transition assessments should be carried out by professionals with experience in autistic spectrum disorders and should include:

- Psychological assessment
- Speech & language assessment
- Occupational assessment
- Learning style assessments
- Functional academic skills assessment

Learning style assessments are valuable in identifying how an individual with an autistic spectrum disorder actually learns (Datlow Smith *et al*, 1995). Some individuals may be visual learners, others may learn by modelling or verbal instruction. Functional academic skills assessments are also necessary to ensure that the individual has guidance in matching skills with future educational and vocational choices.

The assessment process should include information concerning the long term-goals, aspirations and ambitions of the student as identified during the course of second level education. To the extent possible, all persons with autistic spectrum disorder should be interviewed in an effort to discern their individual preferences regarding future educational or vocational options.

Up-to-date information regarding the student's academic, social, communication, emotional, and behavioural skills should also be available. All of the information derived from the assessment process should inform the choices and decisions made by the individual with an autistic spectrum disorder and their parents. While the difficulties of children with Classic Autism may be more obvious, the deficits of adolescents/young adults with Asperger's Syndrome may be subtle in presentation and will need observation during unstructured times when undergoing assessment.

As Klin and Volkmar (1996) point out:

Situations that maximize the significance of the disability include unstructured social situations (particularly with same age peers), and novel situations requiring intuitive or quick-adjusting social problem-solving skills. Therefore, it is important that any evaluation intended to ascertain the need for special services include detailed interviews with parents and professionals

knowledgeable of the child in naturalistic settings (such as home and school), and if possible, direct observations of the child in unstructured periods such as recess or otherwise unsupervised settings.

The NEPS psychologist will have a role in informing the relevant educational authorities when transfer to third level education is proposed. Provision of a detailed report to the counselling/support services in the appropriate institution will be of particular importance in this regard.

9.11 ISSUES RELATING SPECIFICALLY TO PUPILS WITH AS/HFA

9.11.1 Identification

It is crucially important that all students WITH AS/HFA within inclusive second level mainstream settings and special settings should be identified and that appropriate provision should be made for their educational and social needs. The Task Force is seriously concerned that the number of undetected or misdiagnosed Asperger's Syndrome pupils of second level age may be quite high. It is highly likely that some such pupils are inappropriately placed at present. The Report of the Working Group on Asperger's Syndrome (SWAHB, 2001) states that:

Given the complexity of the current diagnosis, it may be the case that many pupils are misdiagnosed or diagnosed at a later stage of their life causing them to miss out on the opportunity of critical early interventions...

Awareness of AS/HFA should be raised among parents and professionals in contact with young people. In particular teachers should be alerted to the possibility that students, who are socially isolated and who are experiencing communication difficulties, may fall within the AS/HFA category. The circulation of an AS/HFA information pack, which includes video and written material, to all mainstream schools would facilitate awareness raising of AS/HFA and an appropriate recommendation on this matter is made elsewhere in this Report.

At school level, the NEPS psychologist will contribute to raising staff awareness of the existence of AS/HFA through working with key counselling and pastoral care staff, and may assist in the development of initial screening instruments which could be used to identify pupils who may possibly need further clinical investigation. It is recognised that great sensitivity would be required in carrying out this work on the part of all concerned, and that any initial indications would be extremely tentative. Following preliminary screening by the relevant NEPS psychologist, pupils who are suspected of falling within the AS/HFA category, should be referred for a multi-disciplinary assessment to the regional ASD referral

and diagnostic service for confirmation or otherwise of the condition. This is further discussed in Chapter 4.

9.11.2 Pupil Retention at Second Level

The majority of students with Asperger's Syndrome do not complete second level education. They drop out of the education system altogether, mainly due to lack of support. One survey (O'Brien, 1997) found that approximately fifty per cent of pupils with Asperger's Syndrome have left the education system by the time they are thirteen years of age. The difficulties experienced by those with AS/HFA are even more problematic during adolescence and adulthood than in the early and primary years (SWAHB, 2001).

Many students with AS/HFA have the intellectual capacity to benefit from second level education. Assessments often reveal that while they may be of average or above-average intelligence, they underachieve significantly in academic areas. The Task Force considers that the discrepancy between ability and attainment in students with AS/HFA should be researched, with a view to identifying effective interventions designed to address this problem. While all students with ASDs would benefit from the provision of support services, including counselling, the Task Force recognises that the availability of such support services will increase the likelihood of retaining students with AS/HFA at second level.

It is very important that support systems operate at a discrete level and with due regard for the sensitivities and right to privacy of individual students. Many adolescents do not wish to be singled out and can often feel further stigmatised by being seen to need assistance. Support sessions with Resource Teachers may, therefore, need to be arranged well away from the peer group in recognition of the enormous efforts of this group to retain their dignity and achieve independence.

Another matter, which needs to be handled with sensitivity, is the issue of informing staff members of an individual's disability status. A policy of informing the student's peers of the disability status of an student with AS/HFA is considered questionable, and should only be effected with the permission of the student and his/her parents.

9.11.3 Social Difficulties

A number of submissions highlight the fact that while students with AS/HFA may in many cases be able to cope with the academic core curriculum and may perhaps be above average in the subjects of interest to them, their social deficit becomes more obvious as they grow older. Students with AS/HFA, therefore, require educational support, delivered by appropriately trained teachers, resource teachers, career guidance counsellors, classroom assistants and educational

psychologists. There is a shortage of information regarding mainstream classroom strategies which accommodate the learning styles of students with AS/HFA.

Bullying routinely prevents students with AS/HFA from attending school and remains a significant causal factor in the high drop out rate at second level. Staff awareness of the vulnerability of students with AS/HFA to bullying is, therefore, extremely important and protective strategies are needed to counteract the long-term immense damage that can be caused to the mental health and well being of this group. In addition to their core condition, they frequently suffer from affective disorders such as depression. Suicide attempts are not unusual for this group particularly during the teenage years.

As bullying appears to be a significant factor in the high AS/HFA drop out rate, the development of policies and measures designed to counteract this problem is extremely important. The Task Force recommends, therefore, that the DES should draft and circulate guidelines on bullying. It also considers that strategies for coping with bullying should be included in modules on AS/HFA in initial teacher training and continuing professional development courses, and a recommendation on this matter is made in Chapter 12.

Many children / adolescents are deeply troubled by their social ineptitude, their lack of social acceptance by peers, and their isolation and rejection. Flexible education is crucial to development and student age / awareness should be given consideration when providing support. As each student will have his/her own distinctive needs and level of social awareness, it is vitally important that 'block solutions' are not identified as appropriate for all people with AS / HFA.

School strategies and support structures need to be put in place immediately for all students with AS/HFA, who are currently enrolled at second level. The NEPS psychologist should advise on appropriate strategies to maximise the child's inclusion in the social life of the school.

9.11.4 Social Skills Training

Social integration within a peer group is an essential step to being accepted by society. Peers often display an instinctive awareness of the 'social differences' in pupils with AS/HFA, which may go unnoticed or be dismissed by adults. The alienation experienced by people with AS/HFA would be greatly alleviated by the provision of social skills groups at second level. Regular self- help and discussion groups would also facilitate the development of social and communication skills and provide leisure and social opportunities for this group.

Many teenagers with AS/HFA have the same aspirations and capacity to learn as the rest of society, namely to be successful, have friends, enter into relationships

and to achieve a sense of belonging. Appropriately trained professionals (e.g. psychologists) could introduce advice and discussion on friendship, relationships, problem solving and general life skills in a manner, which would not offend the dignity of this extremely aware group.

The Task Force recommends that all persons diagnosed as AS/HFA should have access to age appropriate social, communication and life skill training programmes across the range of educational settings. Where late diagnosis is made during adolescence/adulthood, such intervention programmes should be implemented immediately.

9.11.5 Social Inclusion/Community Integration

Adolescence is a time when community integration is of particular importance. All support for young people with AS/HFA should, therefore, have a strong in-built community dimension. The need for routine and familiarity are crucial factors in reducing anxiety and stress levels among this group and it is logical to assume that opportunities for achieving academic, emotional and social success and independence will be enhanced in a familiar setting. Difficulties experienced by people with AS/HFA regarding integration with peer groups also indicate the need for local community provision. Family support remains an important factor in the social lives of many people with this condition. Students with AS/HFA should be supported and facilitated to develop a normal pattern of life in their own communities.

Social inclusion and full participation should be encouraged and facilitated by the provision of paid advocates who would operate in an advisory capacity and accompany individuals with AS/HFA on social outings/community activities. For many adolescents and young adults with AS/HFA, too much time spent focused on their difficulties may have adverse effects on their strengths. It is important to create opportunities for the development of individual strengths and to broaden their range of interests whilst seeking to improve communication and social understanding.

The report of the Working party on Asperger's Syndrome (SWAHB, 2001), highlights the need to recognise that adolescents with AS/HFA in second level education experience even more difficulties at this stage than during the primary and early years. The Task Force endorses this view, and recognises that many students with AS/HFA are likely to miss out on early intervention initiatives due to difficulties surrounding diagnosis. The Task Force, therefore, recommends that the social and educational needs of students with AS/HFA at second level should be prioritised by all those providing services to this category.

Many people with AS/HFA are late reaching maturity, and should be given every opportunity to develop at their own pace with the continuing provision of

education/therapeutic support. The acquisition of new skills and improvements in levels of communication and independence often continue well into adult life. With appropriate levels of support and opportunities for further education, many people with AS/HFA are capable of leading full and productive lives. Unaided, many of this group may deteriorate to a point where they may need long term residential/ psychiatric care at the expense of their potential abilities and at considerable expense to the State.

The implications are clear. This is a vulnerable high risk group in urgent need of help. They are more disabled in many ways by the attitudes of society, neglect of State services and lack of support, than by their core disability.

10. Recommendations

The Task Force recommends:

1. that there be a flexible continuum of educational options for pupils with ASDs at second level;
2. that there be a range of differentiated models of provision for students with an ASD in respect of the two categories of autistic disorder and AS/HFA;
3. that following the multi-disciplinary assessment to be carried out prior to completion of the primary stage, the proposed Special Needs Organiser or appropriate Department of Education and Science officer have the responsibility, with parental agreement, for identifying and securing an appropriate post-primary placement for students with ASDs;
4. that entitlements/supports attached to each child, subject to appropriate modification, be automatically transferred to the next educational setting;
5. that any additional resources allocated to a pupil with an ASD be ring-fenced in respect of that pupil;
6. that support services be fully accessible to all pupils with ASDs, irrespective of whether their educational placement is in home-based, mainstream or special settings;
7. that the Department of Education and Science issue and circulate written guidelines outlining the necessity of regular home/school liaison in respect of students with ASDs;

8. that the Department of Education and Science urgently reviews the practice of attaching explanatory notes regarding special arrangements in Examinations to the candidate's certificate of results;
9. that there be a significant increase in projected NEPS staffing levels to enable the educational psychologists to have a meaningful role in working with pupils with ASDs;
10. that the Department of Education and Science produce and circulate guidelines on bullying to schools;
11. that the effectiveness of provision for students with ASDs in second level schools be regularly monitored and annually reported on by the Department of Education and Science Inspectorate;
12. that second level placement recommendations be based upon a 'least restricted environment' philosophy and a presumption of local provision;
13. that all post primary students with ASDs have access to the most appropriate curriculum and accreditation route to match their ability and direction;
14. that the proposed Visiting Teacher Service for ASDs continue to play an important function in supporting pupils with ASDs at second level;
15. that preparation and planning for post second level education be a basic component of the student's individual education plan at second level;
16. that a review of the post second level transition plan take place at approximately fourteen years of age, or not later than the end of the Junior Cycle stage;
17. that a comprehensive independent multi-disciplinary assessment be carried out on all pupils with ASDs as they approach the completion of post primary education;
18. that the discrepancy between ability and attainment in students with AS/HFA be researched, with a view to identifying effective interventions designed to address this problem;
19. that particular attention needs to be devoted to providing support systems, including counselling, for all students with ASDs, which will, in particular, increase the likelihood of retaining students with AS/HFA at second level;
20. that all persons diagnosed as AS/HFA have access to age appropriate social, communication and life skill training programmes across the range of educational settings;

21. that the social and educational needs of students with AS/HFA at second level be prioritised by all those providing services to this category.
22. that community integration should be encouraged and facilitated by the provision of paid advocates who would operate in an advisory capacity and accompany individuals with AS/HFA on social outings/community activities.

CHAPTER 10

THIRD LEVEL AND CONTINUING EDUCATION

10.1 INTRODUCTION

This Chapter will outline the relevance and history of adult education and training for persons with autistic spectrum disorders, the history of such education and training in Ireland, and the need for a wide variety of educational opportunities and programmes to be developed across the spectrum for the post secondary age group.

As with all levels of education and support, late adolescents/adults with an ASD will present with a very wide spectrum of symptoms, strengths, and needs. Some will fall into the range of severe intellectual disability and require lifelong residential support and sheltered education and training programmes. Others will attend universities, receive professional qualifications and post-graduate degrees, marry and have families. The majority will fall somewhere between these two extremes. Historically, the late adolescent/adult educational needs of individuals diagnosed with ASDs have been neglected. Many adults with ASDs in Ireland are still unidentified by State agencies. They are without any organised purposeful daily activities, support or educational opportunities.

If current knowledge gained from international research and experimental studies is widely disseminated and used to influence the planning of future educational provision, the outcome for those affected by these disorders may improve considerably. Attitudes are changing, albeit slowly. Assumptions, perceptions and narrow expectations may now be replaced by more accurate information and understanding. Low awareness of these conditions in the past routinely resulted in failure to develop, adapt or deliver curricula, programmes and support to those in need of assistance. Schools, colleges, training centres (mainstream and special) and adult programmes lacked the knowledge, understanding, expertise and motivation required to create a suitable learning environment for this group. This has resulted in severely restricted levels of access, participation and outcome for adolescents/adults with autistic spectrum disorders in Ireland. The views of two individuals with ASDs offer interesting insights:

I drove 1,200 miles to the 10th annual TEACCH conference, where I learned that autistic people can't drive...Assumptions are usually much more resistant to learning than my ignorance (Sinclair, 1992.pp.294-302).

I like to say aspies are not defective, but rather we are different; differently able if you will.....Pushed further, I would assert we aspies are fine like we are, or at least we would be, if only society would learn to be more accepting and empathetic toward the a-

typical. I know this type of world could exist, I've seen it (Willey, 2001. p. 139).

10.2. LIFELONG LEARNING

10.2.1 The European Commission's *Memorandum on Lifelong Learning* (2000)

The '*Memorandum on Lifelong Learning*' produced by the European Commission (2000) has initiated a Community debate which is timely in the context of the mainstreaming of services for individuals with disabilities. There are six key messages in the *Memorandum*, which offer a framework on making lifelong learning a reality for everyone in Europe:

1. New basic skills - the gaining and renewing of skills for sustained participation in the knowledge society, which demands a guarantee of universal and continuous access to learning. Particularly important are IT skills, foreign languages, technological culture, entrepreneurship and social skills.
2. Raising levels of investment in human resources.
3. Innovation in teaching and learning - effective teaching and learning methods and contexts for the continuum of lifelong and 'life-wide' learning.
4. Valuing learning - the need for understanding and appreciation of participation and outcomes, especially in non-formal and informal learning.
5. Guidance and information - provision of easy access to good quality information and advice about learning opportunities for all ages.
6. Bringing learning closer to home - providing lifelong learning opportunities as close to learners as possible (<http://europa.eu.int/comm/education/life/>).

The European Commission's definition of life long learning as '*all purposeful learning activity undertaken on an ongoing basis with the aim of improving knowledge, skills and competence*' is all embracing and encompasses:

- all learning "from cradle to grave", from the early years through adult life - including the Third Age - encompassing a common core of knowledge and skills which goes beyond basic numeracy and literacy;
- not only employment-related skills, but also the updating of all kinds of abilities, interests, knowledge and understanding throughout life;
- all kinds of learning, including non-formal (such as acquiring vocational skills at the workplace or language skills from participating in a study circle organised by an NGO) and informal skills (such as learning how to play football or an instrument together with friends).

Lifelong learning is as much about providing "second chances" to update basic skills as it is about offering learning opportunities at more advanced levels. The final purposes are to develop active citizenship, employability, adaptability, social inclusion and individual fulfilment. (<http://europa.eu.int/comm/education/life/>)

The Task Force strongly endorse the aims of the *Memorandum on Lifelong Learning* and the work of the European Commission in this regard.

10.3 RIGHTS WITHIN VOCATIONAL AND THIRD LEVEL EDUCATION

There are three Acts, which have particular implications for vocational and third level education. These Acts identify rights gained by students and responsibilities that are owed by colleges, and academics to students as a result of legislation (see below and also Chapter 14 and Appendix 18).

10.3.1 Employment Equality Act, 1998

The Employment Equality Act (1998) prohibits discrimination in vocational training and 'vocational training' means any system of instruction which enables a person being instructed to acquire, maintain, bring up to date or perfect the knowledge or technical capacity required for the carrying on of an occupational activity and which may be considered as exclusively concerned with training for such an activity. The protection in respect of vocational training is available to all persons between fifteen and sixty-five. This Act states that providers of vocational training shall not discriminate in relation to people applying for a course.

10.3.2 The Universities Act, 1997

The Universities Act is predominantly concerned with the running and governance of universities. It links equality of opportunity and access to the university, and reinforces the obligation on the university to promote university education to those underrepresented within university life at present. The Act also specifies that the Governing Authority must aim to attain equality of opportunity among the student body. This is important as it not only argues for the mainstreaming of education provisions for students with disabilities, but also that the equality policy must consider the disability concerns among them. The Act places a requirement on universities that they implement policies in respect of access to the university.

10.3.3 The Equal Status Act, 2000

The Equal Status Act prohibits discrimination at 'educational establishments' (Section 7). The definition of 'educational establishment' includes '*an institution providing adult, continuing or further education, or a university or any third level or higher level institution, whether or not supported by public funds*'. There are derogations specific to disability within this act (see Chapter 14 and Appendix 18).

10.4 RECENT DEVELOPMENTS

10.4.1 Transfer of Responsibilities for Vocational Training

The guiding principles of The Report of The Commission on the Status of People with Disabilities (*A Strategy for Equality*, 1996) include equality, maximising participation, enabling independence and choice through the adoption of a social model of disability. The recommendation that a mainstreaming approach to issues relating to disability should be adopted, resulted in the dissolution of the National Rehabilitation Board (NRB). An establishment group was set up to prepare proposals, which included the future location of departmental responsibility for the executive functions of the NRB (the statutory agency responsible for training, advocacy and the dissemination of information to people with disabilities).

The Establishment group recommended that participants of Level 1r training courses who did not demonstrate the ability to progress to further training, and were in need of training of a rehabilitative nature, would remain the responsibility of the Department of Health (health service/LD day programmes and rehabilitative workshops and training courses) while responsibility for remaining vocational training, which includes part of Level 1(level 1v) and all of Levels 2 and 3 training should transfer from the Department of Health to the Department of Enterprise, Trade & Employment under FAS. The target time-scale for the transfer of responsibilities designated the year 2000 as the transition period and 2001-2003 as the implementation period.

10.4.2 New Councils to Award Degrees, Diplomas and Certificates

The Minister for Education and Science Dr. Michael Woods, TD established two new awarding Councils in 2001. Degrees, Diplomas and National Certificates will be awarded by two new bodies (1) The Further Education and Training Awards Council (FETAC), and (2) the Higher Education and Training Awards Council (HETAC).

Speaking at the launch, Dr. Woods said *‘The Awards made will be fully recognised both nationally and internationally. They will also provide for progression and transfer of students, with full recognition for their studies to date, to Institutes and Universities. Courses provided by FAS, CERT and Teagasc will now be validated through the new Councils. Existing universities and the Dublin Institute of Technology will continue with their existing arrangements for certification. All other institutes and educational establishments will come under the new Councils.’*

The two new awarding Councils have three principal functions:

- the establishment of policies and criteria for the making of awards and the validation of programmes;
- the determination of standards of knowledge, skill or competence to be acquired by learners, before an award may be made by a Council or recognised by a Council;

- the making and recognition of awards where people have achieved the required standards as set out. Ensuring the quality of awards is central to the task confronting the incoming Councils (<http://www.fetac.ie/>)

10.4.3 HETAC (the Higher Education and Training Awards Council 2001)

HETAC was established under the Qualifications (Education and Training) Act 1999. HETAC is the qualifications awarding body for third-level educational and training institutions outside the university sector. It is the legal successor to the National Council for Educational Awards (NCEA). HETAC may delegate authority to make awards to Recognised Institutions under the Act. Recognised Institutions currently comprise the Institutes of Technology.

In assuming the main functions of NCEA, HETAC will continue to take a modern, progressive approach to third-level education. While it will undertake the validation of programmes, and set and monitor standards, HETAC will take a more strategic view of Quality Assurance in higher education and training. It is also charged with ensuring that student assessment procedures within institutions are fair and consistent, and ensuring academic and financial protection for students in commercial educational institutions providing programmes validated by HETAC. It will also monitor the educational needs of the economy for all extra-university higher education and training bodies and institutions (<http://www.hetac.ie/>)

10.4.4 FETAC (Further Education and Training Awards Council 2001)

Under legislation, the Further Education and Training Awards Council (FETAC) will make and promote awards of high quality, validate the quality of programmes, set national standards and establish working partnerships drawing together industry, education and training interests. FETAC will carry out the functions of the former National Council for Vocational Awards and replace the certification sections of CERT/NCTB, FAS, Teagasc and BIM. FETAC unifies former certification agencies under one banner (<http://www.fetac.ie/>).

10.4.5 The Supreme Court's Decision

The Supreme Court's July 2001 decision (Sinnott case appeal) that the State's constitutional obligation to provide a primary education ends at age eighteen, creates the need for an effective Civil Rights Statute, dealing with the educational rights of persons with disabilities, which will allow for, and oblige the State to, provide an age appropriate and disability specific education for as long as the individual may require and benefit from it, lifelong if need be. This is very strongly advocated by the Task Force on Autism.

The research literature has identified that appropriate educational opportunities are key factors in achieving positive outcomes for those with an ASD. Comparison studies indicate marked improvements between 1960 and 2000, with a decline in institutional care and some increases in employment opportunities (Howlin and Goode, 1998). Kunce and Mesibov (1998) note that appropriately structured educational programmes may influence later

academic and occupational attainments, while Lord and Ventner (1992) stress that the adequacy of local provision may also have a significant impact on outcome. As will be outlined below, support services generally for adults with ASD in Ireland are available for very few.

10.5 THE CURRENT POSITION

10.5.1 Further and Continuing Educational Opportunities

Individuals with ASDs generally, are a marginalised and extremely vulnerable group. For parents of less able autistic adolescents and adults, there is considerable anxiety as they learn of lengthy waiting lists for the very few post-eighteen years autism-specific services available in this country. This is the point at which some students who have been identified as having autistic disorder may sometimes be categorised as having an intellectual disability as their primary diagnosis, in an effort to be eligible for an existing service. Some of those with autistic disorder have access to continuing education, training and shelter under the provision of designated intellectual disability or autism service providers, but many placements are far from their local communities and families. Some of those with AS/HFA are misplaced due to the current lack of dedicated services and support structures. This group do not generally meet the eligibility criteria for learning disability and adult autism specific services (due to average IQ levels), which are designed for those who are lower functioning and are, therefore, unable to meet the differing needs of those with AS/HFA. Submissions to the Task Force, such as the two below, have repeatedly highlighted the need for lifelong education/training opportunities for people with ASDs:-

There is a serious education deficit for present teenagers. They have been denied an education and a serious debt is owed to them. Adult education is needed for these people.

Education for autistic people cannot stop at eighteen or twenty-one. The nature of the disability makes it imperative that improvements of quality of life and development of potential are lifelong activities and must be supported as such.

Opportunities for continuing education and vocational training are severely limited across the spectrum. In spite of the existing potential for success, the numbers of persons with ASDs involved in supported employment initiatives and inclusive activities are far from encouraging. In the absence of State supported dedicated services in many regions, the vast majority of late adolescents/adults with ASDs do not have access to social skills groups, leisure activities, age and ability appropriate educational/vocational opportunities, therapeutic intervention, supported living, or supported employment.

A research survey carried out by the UK National Autistic Society (2001) has identified numerous areas of concern regarding the plight of adults with ASDs due to lack of joint responsibility to meet their needs. Information from the

450 respondents indicates that only two per cent of adults at the lower end of the autistic spectrum and only twelve per cent of adults with AS/HFA are in full-time paid employment. A quarter of the adults in the survey is doing nothing at all or is 'helping out around the house'. Evidence to the Task Force suggests that the findings of this survey are relevant, and equally applicable to the Irish context. The survey states that: -

But most of all this survey throws into sharp focus the lonely, lengthy and confusing battle for services which faces people with autism and Asperger's Syndrome, and their carers, at the transition from childhood into adulthood. The Government policy of inclusion within the education system is raising expectations, which are only shattered in adulthood, as current provision is woefully inadequate. The crucial years of transition can make the difference between an unhappy and dependent existence in adulthood, or a more independent and fulfilled life (National Autistic Society, 2001. P. 24).

10.5.2 Participation in Higher Education

A London based study (Howlin *et al*, 1998) shows that very few individuals with ASDs, including those with normal intellectual ability, gain any formal qualifications at school. Information gained from those in contact with ASPIRE (the Asperger's Syndrome Association of Ireland), reflects this pattern and indicates that many persons with AS/HFA exit the second level education system with little or no certification, despite average/ high levels of academic ability. A recent survey of thirteen young adults with Asperger Syndrome in the Midwest of Ireland (Farrelly, 2001) also reflects such findings and highlights concerns raised in submissions to the Task Force;

The survey does underline and echo the major themes in the literature...the significant difficulties experienced in the education system, the social isolation and the high dependency on families for support and care. The high levels of psychological difficulty reported and the apparent absence of multidisciplinary services are areas that need to be addressed. Many of the people are staying at home or participating in training programmes that are perceived as inappropriate to their needs (Farrelly, 2001. p.26-27).

Many of those with AS/HFA who cope in mainstream classes and schools, struggle on a daily basis and overcome enormous obstacles throughout the course of second level education only to find that on completion, there is little support available to them if they wish to continue their education. In this situation, the aims and gains of 'inclusive education' pursued in childhood are at risk of being reversed in adulthood. Young adults with AS/HFA, many of whom, could successfully participate in mainstream post leaving certificate, further/adult and higher education and vocational training courses, currently have few options, other than placement on sheltered training courses due to

the absence of support structures within such mainstream education/vocational training institutions.

The authorities who decide on entitlement to disability services are sometimes unaware of the extent and significance of the disabilities involved in AS/HFA. Proficient verbal expression skills, overall IQ within the normal or above normal range, and a solitary lifestyle often mask outstanding deficiencies observed primarily in novel or otherwise socially demanding situations, thus decreasing other people's perception of their very salient needs for supportive intervention (Klin and Volkmar, 2000. p. 342).

1. In a system where funding is attached to service providers rather than to the individual, there is no clear 'ownership' of the needs of this group following second level education. Although the mainstreaming of disability services does not negate the need for significant support to be provided in mainstream settings, the necessary supports simply do not yet exist. Parents of individuals with AS/HFA who venture into mainstream post secondary education, are routinely left with the onerous task of convincing staff of such education/training institutes and agencies that although their adolescent/adult children may be intellectually able and articulate, they are simply not able to negotiate the social and communication environments without significant support. Unfortunately, attempts of this nature are seldom understood until problems emerge. There is a pressing need for the Departments of Education and Science, Trade, Enterprise and Employment and Health and Children to work in collaboration to ensure that the supports outlined throughout this chapter are provided in the areas of mainstream education/vocational training and therapeutic/counselling support.

Participation rates for students with disabilities in Ireland are substantially lower than in many other EU countries, according to OECD (Organisation for Economic Co-operation and Development) statistics. A survey commissioned by the Higher Education Authority (AHEAD, 2000) indicates that there were 850 students with disabilities attending full-time higher education in this country in 1998/99. This figure represents 0.8 per cent of the total undergraduate population. There are no statistics regarding the participation of students with AS/HFA in higher education in Ireland.

Despite a gradual increase in the 1990's in the numbers of students with disabilities attending higher education in Ireland, evidence to the Task Force indicates that individuals with AS/HFA are severely under represented in this area. The difficulties commonly encountered include:

- The inflexibility of the points system;
- Inconsistency in admission procedures;
- Lack of published admissions policy on disability in some institutions;
- Low awareness of AS/HFA among staff of post leaving certificate, further/adult and higher education institutions;
- Inadequate support structures;
- Lack of advocacy services;

- Lack of funding for personal assistants;
- Absence of appropriate grant schemes;
- The absence of a one-stop ASD information/advisory service to co-ordinate daily living entitlements/grants/ancillary supports which may be needed to facilitate entry to higher education.

Additionally, some students are not provided with a definite diagnosis of AS/HFA prior to attending higher education. Others may be very reluctant to disclose AS/HFA on their application forms.

10.5.3 Interdepartmental Collaboration and Co-ordination

It is vitally important that services for persons with ASDs proceed on a basis of partnership between the Departments of Health and Children, Trade, Enterprise and Employment, Social, Community and Family Affairs, Finance, and Education and Science. Difficulties that routinely arise due to lack of co-ordination and strategic planning between departments result in fragmented service delivery or in many cases, no service delivery at all. This problem has been outlined throughout this report and in many past reports including SERC (1996) and the report of The Commission on the Status of People with Disabilities (1996). Collective departmental responsibility and inter-departmental collaboration are needed to ensure that a range of supports is in place to assist late adolescents/adults with ASDs to maximise their potential and in doing so, achieve a good quality of life. Co-ordinated inter-agency assistance, planned collectively by a variety of government departments and delivered with consistency and sensitivity by professionals and staff who are aware of both the underlying potential and the social, communication and inflexibility deficits associated with ASDs are critical if gains are to be achieved. As noted earlier in this report, submissions to the Task Force have repeatedly alluded to the existing lack of co-ordination and planning between Government Departments; -

There should be a coordination of services between the Departments of Health and Education. The needs of autistic children need to be addressed in a coordinated manner by both government departments-with individualised programmes of intervention for each child and a reporting mechanism to ensure that they are being implemented.

Finally it is vitally important that services proceed on a basis of partnership between health and education.

The most frustrating for us as parents is that there is no clear co-ordinated approach to these matters by the State. Things seem to happen almost on an ad hoc basis....

Some of the difficulties that routinely arise for adolescents/adults with ASDs are of an administrative nature, and yet cause undue problems. The entitlement to a 'bus pass' for those in receipt of 'disability benefit' is one such example as the pass is of no practical use to students due to user restrictions, which stipulate that the pass can only be used during off peak hours. The referral of

individuals with ASDs to towns and locations many miles from their homes for counselling/speech and language therapy is another source of difficulty. This practice applies to individuals who live on the outskirts or suburbs of certain cities but are not eligible for support under the provision of services within walking distance of their homes. Referrals of this nature are meaningless as distance makes it impossible for such individuals to avail of the support on offer. Such referrals are not user friendly, cause more problems than solutions, and operate solely for administrative purposes and to accommodate catchment area and sector requirements of regional health boards.

The inadequacy of educational, vocational and regional health board support services for late adolescents and adults with ASDs has resulted in increasing numbers of parents resorting to the high court to secure a commitment for appropriate intervention. Joint interdepartmental policy will need to be developed to ensure the smooth planning and seamless delivery of a continuum of multi-departmental support services to meet the education, training, intervention, accommodation and social needs of adults with ASDs. Meeting the lifelong learning and living needs of adults with ASD, including the elderly, will be a new concept for Ireland.

10.5.4 Difficulties Encountered Due to Lack of Adult ASD Services

Reports of High Court cases, have highlighted the plight of adolescents and adults with ASDs who do not have access to the education, vocational training, therapeutic, social and accommodation supports that they require to live with dignity and equal status within society. The inadequacy of the response of the State has been clear in such instances. Newspaper reports and Task Force submissions also note that parents of adolescents and adults with ASDs have had no option but to agree to referrals for residential accommodation and support services in England, Wales and Northern Ireland, as the continuum of supports and services required to meet the needs of this population do not yet exist in Ireland.

Submissions to the Task Force have highlighted cases where incarceration in psychiatric institutions or extended residential respite accommodation has been used as an alternative to providing the education, training, employment, community and residential support structures necessary to meet the needs of some individuals with ASDs. In fact, some clinicians also continue to inaccurately diagnose Asperger's Syndrome symptoms as schizophrenia and hospitalise and medicate as a result. Submissions indicate that many families, have now reached crisis point and are unable to cope. Considerable change is warranted to reverse the inequalities of the current system of ad hoc responses by the State. This will require policy adjustments by government departments and the strategic planning and delivery of a holistic range of support services to meet the needs of adolescents and adults with ASDs. Submissions to the ATF outline their concerns as follows:

As a family, we have suffered for over a generation. I hope the Task

Force on Autism, in its final Report will lay the foundation for the provision of all the necessary services, especially in the field of clinical diagnosis and education/training, which will enable those suffering from the disability to contribute in a meaningful way, to the community within which they live, and not be consigned to psychiatric oblivion to live out their sad and lonely lives-under medication-to the sad and bitter end- which to my certain knowledge, was a stark reality in the past.

We would like to draw attention to] the importance of ensuring a smooth transition to post school services, further education, training and other service. In the past six months..... has been approached by parents of young adults leaving special residential school for children with autism in Dublin and the North of Ireland as their children were 'let go' from these schools with no future service on the horizon. Two of these young adults have since ended up in ...(psychiatric Hospitals)

10.6 SHAPING EDUCATION PROVISION FOR ADULTS WITH ASDs

10.6.1 The scope of third level and continuing educational provision

The scope of third level and continuing education provision for individuals with ASDs will need to be flexible and wide ranging to accommodate the diversity of the conditions and the fluctuating needs within the autistic spectrum. It is critical that the differing needs of individuals with autistic disorder and the needs of individuals with AS / HFA are acknowledged and addressed through differentiated courses, supports, and opportunities for learning. The educational, occupational and leisure needs of individuals who are high functioning are different from those with more severe disabilities, although the basic principles of an autism-specific approach may be the same (Howlin, 1997b; Jordan and Powell, 1995; Wing, 1996). The relative strengths and unique disabilities of individuals with Asperger's Syndrome may not be properly addressed by educational programmes designed for those who are much lower functioning (Klin and Volkmar, 2000). Where specialised education/training is required, it should be delivered in an environment where the social, communication, *and* educational needs can be accurately identified and addressed (Howlin, 1997).

It is likely that the majority of persons with ASDs may need others to help them to meet their needs and achieve a better quality of life. This applies, regardless of levels of intelligence as many who are in name living 'independently' still depend on ageing parents for support. However, differences in intellectual ability, language development/ skills, and the severity of autistic impairments are likely to influence both options and outcome significantly. A continuum of flexible support that enables individuals to take up a range of options from third level and post graduate professional courses to supported employment/sheltered employment and

sheltered workshops, all of which incorporate a flexible and phased level of support will be required to address the needs across the spectrum of abilities in both mainstream and specialist settings. Many individuals will live, learn and work exclusively in a range of sheltered environments with mainstreaming occurring in community activities and reverse mainstreaming situations. A significant number of individuals' will also live in the community, work and avail of mainstream educational opportunities (e.g. third level colleges, open employment with support) whilst retaining their 'autistic' impairments and perspectives. The latter group will need considerable support, however, to function in such mainstream settings. The ongoing social and emotional needs of persons with AS/HFA are addressed in chapter 5 and solutions identified will apply throughout the age span.

10.6.2 Inclusion

The philosophy of providing education and training in the *least restrictive environment* outlined in Chapter 1 of this Report applies equally to adults with ASDs. As early childhood, primary and secondary level education becomes increasingly inclusive, the need to ensure that adequate structures and supports are in place when students enter the adult world will be considerable. Inclusion for adults with ASDs will incorporate education, training, vocational/work, leisure and living environments. Once again, it may be accomplished in a variety of ways, depending on individual needs and circumstances.

Inclusive policies will only yield benefits and become a realistic option for adolescents/adults with ASDs when the educational needs are targeted and prioritised across the range of abilities and settings. Inclusion does not occur simply by placing students in mainstream settings; rather it necessitates teaching the person with an ASD the skills necessary to be successful in the inclusive setting, restructuring the environment at times, and the provision of additional and flexible support to overcome the disadvantages which occur as a result of the the impairments of the ASD. Inclusion may be successful when the focus of post-secondary education and vocational training courses and programmes address such life skills, social skills, and quality of life issues in conjunction with academic/vocational training requirements. This will require informed, sensitive, careful, age appropriate and collaborative interdepartmental support, planning, and monitoring. A recent UK publication echoes the concerns expressed throughout the submissions to the Task Force with regard to the shortcomings of current inclusive educational policies:

...But there is a fundamental question: to what end is Inclusion being promoted in education? Our evidence shows that post – 19 there is very little for many adults to look forward to. Are we in danger of setting our children up for failure in adulthood? If we want to match the aspirations of an effective education following early intervention then far more must be done throughout society to change attitudes and raise awareness (National Autistic Society, 2000. p.13).

...There is more that Government can do to promote inclusion, particularly for adults. There is still a huge burden on aging parents. Although their children might have had assessments of their needs, their own needs as carers are often overlooked. Adults themselves need much greater support in obtaining work, for example, support in preparing job applications and at interviews. Employment staff need just as much understanding of the needs of this group as do educators. If it fails here any good work that has gone before will be reduced in value. Adults need more support and guidance in finding opportunities to make friends (some of them structured) if they are to achieve their stated goals: to increase their circle of friendships, and in some cases, to form relationships (National Autistic Society, 2000. p. 13).

In Chapter 14 the Task Force presents its views on the need for Constitutional Amendment to provide for a right to basic education for all, including adults.

10.6.3 Lifelong Learning

It is the considered view of the Task Force that the provision of education and support for persons with ASDs and their families must be considered as a whole of life process because of the uniqueness of their situation and because in today's world education is recognised as a lifelong pursuit. Non-disabled adults in Ireland can avail of lifelong education through formal institutions of higher learning, vocational training, community school education, sports and leisure projects etc. This wide array of options also needs to be made available through the provision of appropriate supports and accommodations to those on the autistic spectrum, and indeed all citizens with a disability. While access to continuing education and training is of the utmost importance to those with ASDs, it is important to note also that personal choices and aspirations must be given due consideration. Adolescents /adults should not be pressurised into 'lifelong training initiatives' and should have the opportunity to make lifestyle choices. The concept of lifelong learning has particular relevance for those with ASDs as many of this group learns at a pace, which is different to that of age peers. Active citizenship, academic success and social inclusion for those with ASDs are largely dependent on access to continuing education and training opportunities throughout life. The employability, independence, and the quality of life of this group are likely to be greatly enhanced by improved access to formal and informal learning opportunities. Research carried out by UK National Autistic Society recommends:

That social services, health and education agencies should take into account the lifelong learning needs of adults when designing their care packages so that education and training continues beyond school and student age (National Autistic Society, 2000. p. 14).

That further and higher education funding bodies recognise that people with autism or Asperger's Syndrome often achieve educational milestones at a different pace from peers and have lifelong educational

and training needs, so that funding should not be time limited
(National Autistic Society, 2000. p. 14).

The Task Force endorses the recommendation by the Commission on the Status for people with Disabilities (1996) that “*there should be full integration of persons with disability in the higher education system, and that appropriate funding provisions should be put in place to support this policy*”(11.50). The Task Force also endorses the Commission’s recommendation that “*transport or alternative support should also be available to students who wish to advance to further education or third level education*”(11.33). The Commission’s recommendation that “*funding should be linked to the student and should follow the student as he or she moves to appropriate educational settings*” (11.63) is also supported by the Task Force.

The needs of carers, including employers in some cases, must also be assessed, respected and receive effective response. There is a huge burden on middle-aged and ageing parents of adults with an ASD. The developmental perspective, intervention and support approach advocated by this Task Force for those with an ASD is also required for parents/carers. To hold or share responsibility for a child, late teenager, or adult with an ASD will require ongoing education to meet the changing needs of their charges, as well as their own needs. Once again, this will require the close collaboration and co-operation of various government departments, particularly Education and Science, Health and Children, Trade, Enterprise and Employment, Social, Community and Family Affairs and Finance.

In sum, the late adolescent/adult with an ASD needs:

- A statutory right to appropriate ongoing education according to individual need;
- ASD adult and family support plan, statutory;
- protective and proactive strategies based on individual presentation;
- access to the support of a mentor/key worker in all education and training settings;
- meaningful leisure and social opportunities with a particular focus on addressing social interactional difficulties within activity oriented groups;
- therapeutic supports. e.g. counselling, speech and language therapy, occupational therapy, behavioural supports;
- Differentiated AS/HFA and Autistic Disorder specific respite and residential options appropriate to individual presentation;

10.6.4 Maximising Learning, Participation & Independence Opportunities

To create an environment, which actively promotes personal development through education, a ‘whole person’ approach should be adopted whereby individuals with ASDs are encouraged, supported and motivated to 'learn to learn'. The learning environment should provide choice, security, structure, acceptance and stimulation. The education//training environment should have flexibility, to allow for periodic steps back without incurring feelings of failure

or inadequacy (Mathews, 1996). Issues surrounding the familiarity and security of local community settings (Howlin, 1997a; Asperger, 1944), social inclusion, maintenance of family relationships (ongoing collaboration with parents will be essential), independence, peer networks, protection, emotional well being and mental health status have implications for the success of all education and training undertaken. Submissions to the Task Force highlight the absence of provision for late adolescents and adults with ASDs, e.g.:

I appreciate that a number of these issues [vocational training, employment, accommodation] are outside your remit as Minister for

Education. However, the initiatives you are putting in place have given us the opportunity to voice our wishes and concerns, and perhaps the hope that you will ensure these are passed on to the relevant people in Government who can make a difference.

We would recommend the development of special education centres within Colleges, including the development of specially developed courses, e.g. in computers, office skills etc. There must be a productive, not aimless use of time. The transfer of skills into the workplace must be proactively supported if placements are to succeed.

Third level and other continuing education settings should not insist on competence in communication or social interaction as part of the teaching/learning process, unless those are the specific skills being taught. There are cases brought to the attention of the Task Force, e.g., where students with ASDs in higher education were deemed to be failing in their courses for reasons, which were said to be 'nothing to do with the disability'. On investigation it was found, for example, that one student had stopped attending classes after being expected to present at a seminar group, not because he did not understand the mathematics problems he was expected to present, but because he was terrified of having to manage the communicative aspects of such an exchange. In the case of a PhD student with an ASD, the tutor had thought she was being helpful in providing additional tutorials to support her 'special needs' student. In practice these frequent tutorials were very disruptive to the student, taking him several days of anxiety building up to the event and being so overwhelmed during the tutorial that no information could be processed. The situation was resolved by stopping all face-to-face tutorials in favour of single-channel telephone tutorials, which the student was able to manage well. The point is that systems of support must take account of ASD difficulties and must be flexible and sensitive enough to respond to individual needs.

- Compensatory vocational training, continuing educational initiatives and interim measures will be essential to meet the education and training needs of those who have been excluded, or dropped out of the education system due to lack of support.
- Post second level transition courses should be provided to develop daily living skills, to prepare individuals for employment,

continuing/further education and independent living and to contribute towards the enhancement of the students' general quality of life.

- Links and collaborative practices with parents will be a vital component of all education and training initiatives if success is to be achieved.

The needs of adults with ASDs cannot be considered simply in the context of academic education. All placements should be age and ability appropriate, respecting the dignity of each person and delivered in a flexible way. Clearly, living arrangements will also have a considerable impact on individual outcome and the motivation / learning skills - whether living independently, at home with families, in semi sheltered apartments, in group homes or communities. Although residential service provision will be appropriate for some persons with ASDs, ongoing support to facilitate a range of options from independent living opportunities, with socially assisted housing, the provision of sheltered housing and supported / semi supported accommodation in the community will also be essential for those whose impairments are less severe. Supported living schemes and out-reach schemes (Lowndes, 1994; Morgan, 1996) which enable people with autistic spectrum disorders to live in homes of their own are needed. Schemes which facilitate choice regarding where the person wishes to live, and assist the individual to negotiate the support they will need to achieve independence, urgently need to be developed by the health boards.

Relaxation and the pursuit of leisure activities are vital to ensure the emotional well being of individuals with autistic spectrum disorders. They are also valid teaching and learning opportunities, which have significant potential to promote social and community integration. Social and communication difficulties may be seriously disabling and marginalising if not addressed through access to continuing therapeutic support, and age and ability appropriate opportunities for continuing education. Development of the communication skills of this group should be a priority for the educational system. People with ASDs may be precluded from accessing many social and leisure activities within their communities. Improved participation is essential in these areas.

10.7 MEETING THE EDUCATION NEEDS OF ADULTS WITH ASDs

10.7.1 Special Fund for Students with Disabilities - Third Level Institutions and PLCs

The Department of Education and Science, with assistance from the European Social Fund, operates a scheme of grants towards the provision of services and the purchase of equipment for students with disabilities attending courses in third level institutions or Post Leaving Certificate Courses (PLCs). The scheme applies to students who have serious sensory, physical and/or communicative disabilities.

The purpose of the scheme is to provide the students in question with assistance and/or equipment to enable them to enter, participate in, and complete their course of study. The following examples indicate the range of provision in respect of which funding has been provided:

Assistance: Personal Assistant, Notetaker;

Services: Transport, photocopying, additional tuition;

Equipment: Computers and specialised software, tape recorders, radio aid.

Please see Appendix 16 for further information.

10.7.2 Lifelong Learning Curriculum

Many individuals with AS/HFA have the capacity to do well academically if supported to do so. Some are, and more could be, successful in formal post-secondary courses, third-level and professional training programmes with the proper level of preparation and support. Others on the spectrum should be afforded education and training compatible with their levels of understanding and practical life needs. Many persons with ASDs need to be taught the basic life skills that are normally acquired intuitively or through imitation. A curriculum for each individual with autistic spectrum disorder should be delineated in their formal Educational Plan. The curriculum should be based on long term goals and incorporate strategies to assist with access to vocational training and/or third level education.

Curriculum components may include:

- Professional and academic courses with support, for the more able;
- The development of academic potential;
- Functional and work-related development;
- Vocational, work and enterprise skills;
- Social communication skills;
- Self-care/self-sufficiency, including making informed choices;
- Independent Living skills;
- Personal and interpersonal relationship skills;
- Computer/IT skills;
- Inclusive and independent recreation and leisure skills;
- Arts/Culture participation, appreciation and enjoyment.

Appropriate curriculum development and continuing education programmes for persons who have an ASD with an additional learning disability might usefully be developed in collaboration with the National Institute for the Study of Learning Difficulties in Trinity College, Dublin, which has the development of appropriate curricular approaches for adults in continuing education as part of its remit.

The use of assistive technology in supporting learning should be facilitated and encouraged. The merits of computer based resources, as a means of

bridging the communication gap experienced by this group should be investigated. Software capable of eliciting and structuring work, and designed to provide the person with clear schedules, task organisers and the promotion of organisational skills may allow the Asperger's Syndrome student, for example, to expand on their thoughts in a way that is not possible when they are required to write their work by hand (Klin and Volkmar, 2000). As many students with ASDs routinely under-achieve due to the inadequacy of traditional methods of teaching to meet their special needs, the provision of grant aid for computers for individual students would be of enormous benefit in enhancing opportunities for learning without the constant stress of social interaction and peer pressure.

Regardless of the level of cognitive and behavioural functioning, all of the above can be successfully included in the adult learner's day. All approaches should be tailored to the needs of each individual, provide opportunities for them to make informed choices, and promote independence at levels appropriate to the age and ability of each person. Where applicable, the curriculum should also include modules that specifically strengthen those areas, which are barriers to integration and gainful employment, such as:

- Interviewing skills
- Coping strategies/stress management
- Job retention skills
- Role and duties of employment/employee
- Relationships with co-workers
- Organising of non-working periods

10.7.3 The Educational Statement/ASD Adult Family Support Plan

The Educational/Vocational Training Statement should address the:

- educational /Vocational Training needs of the person (curriculum);
- desired outcome;
- best possible and appropriate methods;
- environment or setting for each structured learning opportunity;
- specialist staff required;
- frequency of evaluation;
- other identified issues.

The ASD Adult and Family Support Plans should be co-ordinated with the Educational/Vocational Training statement and further address:

- Accommodation/residential and respite needs
- educational and occupational guidance and counselling
- social needs
- therapeutic needs
- mental health needs

10.7.4 Treatment & Intervention Guidelines for AS/HFA

Among the programme specifications outlined by Klin and Volkmar (2000) as optimal conditions for treatment and intervention for Asperger's Syndrome are the following guidelines:

- Adults with AS/HFA may fail to meet entry requirements (e.g. a college degree) for jobs in their area of training, or fail to attain a job because of their poor interview skills, social disabilities, eccentricities, or anxiety attacks. Having failed to secure skilled employment, commensurate with their level of instruction and training, sometimes these individuals may be helped by well-meaning friends or relatives to find a manual job. As a result of their typically very poor visual-motor skills they once again fail, leading to devastating emotional implications. It is important, therefore that individuals with AS/HFA are trained for and placed in jobs for which they are not neuropsychologically impaired, and in which they will enjoy a certain degree of support. It is also preferable that the job does not involve intensive social demands. As originally emphasised by Hans Asperger, there is a need to foster the development of existent talents and special interests in a way as to transform them into marketable skills. However, only part of the task is to secure and maintain a work placement. Equal attention should be paid to social demands defined by the nature of the job, including what to do during meal breaks, contact with other workers, *or* any other unstructured activity requiring social adjustment or improvisation (Klin and Volkmar, 2000).
- The availability of a sensitive counsellor who can focus on the individual's emotional well being, and who could serve as a co-ordinator of services, monitoring progress, serving as a resource to other staff members, and providing effective and supportive liaison with the family.
- Emphasis should be placed on skills that correspond to relative strengths for the individual as well as skills that may be viewed as central for the person's future vocational life (e.g. writing skills, computer skills, transport schedules, science). If the individual has an area of special interest that is not as circumscribed and unusual as to prevent utilisation in prospective employment, such an interest or talent should be cultivated in a systematic fashion, helping the individual learn strategies of learning (e.g., library, computerized data bases, Internet, etc.), it is often useful to emphasise the utilisation of computer resources, with a view to: (a) compensate for typical difficulties in grapho-motor skills; (b) to foster motivation in self taught strategies of learning including the use of "on-line" resources; and (c) to establish contact via electronic mail and with other people who share some interests, a more non-threatening form of social contact that may evolve into relationships, including personal contact, contact with the public or co-workers, or any other unstructured activity requiring social adjustment or improvisation (Klin and Volkmar, 2000).

All adults with ASDs need more support and guidance in finding opportunities to increase their circle of friendships, and in some cases, to form relationships (National Autistic Society, 2000). People with AS/HFA in particular can learn socially acceptable behaviour patterns. Those with more severe autism or related developmental disability, also make continuous progress towards improved social skills when provided with the relevant support, training and environments.

10.7.5 Post-Secondary Education/Training Options

. ... If those who are high functioning are to be given the opportunity to make the most of the skills which they undoubtedly possess, much more is required in terms of appropriate educational facilities, help with supported living and accommodation and the development of wider social support networks (Howlin, 2000. p. 79).

Continuing adolescent/adult education and vocational training provides an opportunity to develop 'special interests' and transform them into useful skills, which will assist individuals to live satisfying and productive lives while at the same time providing them with the opportunity to contribute to society. Sadly, the lack of understanding and the mostly unstructured settings in the adult world, make this more problematic. Some individuals may be able to participate in third level / higher education courses or employment following second level education if support is provided. However, many others may need a more gradual transition.

There is a wide range of mainstream post secondary education /vocational training options which have the potential to meet the needs of some persons with ASDs if appropriate supports are in place. While these options may be chosen with a view to realising vocational objectives, for some individuals with AS / HFA, they may also represent an alternative access route to higher education and can prove to be a valid and gradual 'stepping stone' to third level certificate, diploma and degree courses. The importance of providing support to encourage and facilitate individuals to avail of this 'gradually paced' avenue of entry to higher education should not be overlooked in view of the fact that so many individuals with AS / HFA do not have any second level academic certification despite their generally average/high levels of intellectual ability. Regardless of the access route taken, it is clear that support will be needed throughout the range of options and settings, which include: -

- second level schools
- third-level institutions
- community education classes
- distance education initiatives (e.g. the open university)
- mainstream vocational training institutions
- work placements

10.7.6 The National Vocational Certificate Level 1

Level 1 courses offer certification at introductory vocational level. It recognises achievement in personal and vocational skills, knowledge and understanding. The focus is on learning which will enable the

learner to progress to employment or further education and training. The National Vocational Certificate Level 1 is awarded to participants who achieve the required standard in eight modules:

- communication
- a personal skills module
- mathematics
- information technology
- 4 elective modules.

10.7.7 National Vocational Certificate Level 2

Participants are required to successfully complete 8 modules, (Each module is a building block carrying what is known as a 'credit value'. These credit values are added together to make up a certificate (8 credit values). Credit values can be added together over a period of time. For each module successfully completed, participants are awarded a Record of Achievement.) To achieve a National Vocational Certificate, Level 2, participants must combine:

- 5 vocational modules,
- 1 communications module,
- 1 general studies module,
- 1 work experience module.

The National Vocational Certificate Level 2 is designed to equip people with the skills needed for direct entry to employment, and for progression to higher education or training. Access to Level 2 programmes is open to people who have completed National Vocational Certificate Level 1, Leaving Certificate or equivalent. There is a range of National Vocational Certificates at Level 2 leading to careers in

- Art, Craft and Design
- Business and Administration
- Science, Technology and Natural Resources
- Services, Leisure and Tourism
- Communications, Performing Arts and General Studies

The most common way of completing a National Vocational Certificate, Level 2, is through a school or centre as part of a post Leaving Certificate course (PLC). Post leaving certificate courses are designed to cater to those who have completed the Leaving Certificate/Leaving Certificate Applied/Leaving Certificate Vocational Courses. A list of centres/colleges offering post-leaving

certificate courses many of which lead to NCVA certification can be found on Scoilnet at the following address www.ncte.ie/plc

Many of these courses are run on a full-time basis, however the NCVA certificate (to become a FETAC Certificate from 2001) is designed to allow flexibility in terms of learning and provision. More and more centres are offering courses on a part-time basis, in the evenings and at weekends. This flexible system has resulted in a large increase in the number of adults achieving NCVA awards. The National Vocational Certificate Level 2 is designed so that specific vocational skills are supported by broader skills such as:

- communications
- teamwork and negotiation skills
- problem solving skills
- initiative
- decision making skills
- familiarity with new technology
- flexibility, adaptability
- workplace practice

A National Vocational Certificate (FETAC Certificate) Level 2 is awarded to a candidate who achieves the required standard in eight modules, as specified for the particular certificate <http://www.ncva.ie/>.

10.7.8 The Higher Education Links Scheme

This access route to higher education enables learners who have achieved National Vocational Certification at Level 2 to apply for a higher education place in a range of higher education institutions. Higher education is defined as a process of formal education at tertiary levels, which includes certificate, diploma, and degree courses at the undergraduate level, together with postgraduate and research programmes.

Higher Education Links Scheme (HELs) applicants submit their third-level applications to the CAO in the usual way. NCVA Level 2 results are issued to the CAO and the participating institutions. Applicants through the scheme are assessed as follows: Each NCVA module is credited, with three points allocated for a distinction, two points allocated for a merit and one point allocated for a pass.

10.7.9 Third Level Education

Third level, further/adult and post leaving certificate courses are realistic and viable options for some persons with ASDs and particularly some of those with AS/HFA. Intellectual ability, a tendency toward routine, observation of rules, and the focus of narrow interests are among the potentially positive factors for academic success and employability. Admissions procedures are variable and differ across the range of higher education institutions. The Central Applications Office (CAO) processes applications for third level/higher education courses in Ireland. Students with disabilities have the option of completing a 'Special Category' box on the CAO application form. This procedure alerts institutions to the special needs of some students in order

to facilitate the provision of supports for each individual, while also flagging the potential entry. Everyone has to apply through the CAO, although some colleges also offer a direct entry route.

Standard Entry

This term is used to refer to students who obtain, or expect to obtain, the necessary Leaving Certificate points and qualify for a place in a third level programme of their choice. Many students with disabilities will fulfil the necessary criteria to gain a place on a third level programme through the standard route (AHEAD 2000).

Non-Standard Entry

This term refers to transfer applicants; mature applicants (23+); applicants for part-time (or evening) degree programmes; applicants for a degree programme not included in the CAO Handbook; applicants for a year other than the first year in any programme; occasional or visiting applicants and applicants with a disability. This alternative entry route represents an opportunity to gain access to third level education for many students who cannot compete at an equal level in the points race, (AHEAD, 2000). Students with disabilities may qualify for a non-standard third level place if,

1. because of their disability, learning or health difficulty, they cannot compete equally in the Leaving Certificate Examination and, as a result, do not fulfill the necessary admissions criteria to gain a place through the standard route.

or

2. they are 23+ years and qualify for entry on mature grounds.

In all cases (standard and non-standard), third level institutions have the discretion to admit a student when they accept that the disability prevented that student from gaining the minimum entry points and are satisfied that the applicant is academically able for the course (AHEAD, 2000).

Post Leaving Certificate, Further Education and Third-level support schemes for people with AS/ HFA should be implemented throughout the country on a regional basis. The existing third level access programme for students from disadvantaged areas may provide a model for including those with an ASD. In order to ensure opportunities for ongoing education are a realistic option for persons with AS/HFA, it is critical that practical support is identified to improve access and retention rates and provide the support necessary for students to complete their chosen courses.

10.7.10 Prospects (UK) Student Support for Asperger Syndrome

The Prospects (National Autistic Society, UK) student support service for people with Asperger syndrome is an initiative, which provides specialist support and guidance to students with Asperger Syndrome and their place of learning. Advice and information is given by employment consultants to help

to develop an understanding of the difficulties people with Asperger Syndrome may face with regards to their studies. They also work on a one to one basis with the student and liaise with staff and peers. Help is also given in setting up support networks such as mentors and providing effective strategies to aid independent learning. There are currently 70 people registered with Prospects, in paid employment, work experience, 1:1 guidance or university support.

There is a need for the establishment of secondary school to college transition courses and student support schemes (e.g. Prospects), to prepare individuals for the demands of higher education courses. The Task Force recommends that a similar student support scheme should be established in Ireland.

For those who will not be in a position to secure a degree or formal qualification, they might still be included by auditing (sitting in on) some courses that are of particular interest to them.

10.7.11 Identifying Mainstream Accommodations

Understandably, the needs of children with autism and the support services available to address these needs- from special education schools, to model programs and research data on intervention approaches- have become associated with a profile of severe social disability usually accompanied by equally severe cognitive and language limitations and behavioural challenges. As a result, parents of individuals with AS [and HFA] often find themselves unable to profit from the considerable resources associated with the term 'autism' because their children's needs and challenges as well as their strengths are quite different. This historical development has resulted in a void of support services for more able children with social disabilities and their families, who, to some extent, have become orphans in a system primarily categorised in terms of autism on the one hand and the more academically based learning difficulties or mainstream education on the other hand (Klin and Volkmar, 2000).

For late adolescents and adults with AS/HFA who wish to pursue mainstream third level, further/adult and post secondary education opportunities and mainstream vocational training courses, there are a number of practical considerations that merit attention. The pursuit of post secondary education incurs financial and personal costs that are prohibitive to many people with AS/HFA and their families. The Task Force has identified the need for substantial interdepartmental and interagency support and assistance to be provided to those pursuing mainstream post secondary education/training at all levels. In order to ensure equality of educational/vocational opportunities opportunity any or all of the following supports may be required in mainstream education settings:

- Legal advice for prospective students;
- Provision of personal assistants;
- Befrienders/mentors/advocates;
- Transport arrangements;

- Accommodation (sheltered, semi-sheltered and open);
- Grants for courses;
- Extra tuition;
- Counselling and therapeutic support;
- Leisure opportunities;
- Opportunities to participate in social skills/understanding groups;
- Provision of material aid to support learning (e.g. computers, written lecture notes etc.);
- Specialist support workers;
- Funding attached to the individual (as opposed to services);
- On-going support with independent living, communication, social understanding/skills groups, advice, guidance, and personal safety issues(through collaboration with local ASD intervention services).

The need for structure and routine can be addressed by careful organisation of the timetable to structure both the academic schedule and the student's/trainee's free time, e.g. use of the sports centre, library, computer room, etc. Mentoring schemes can also be extremely helpful. The following strategies may be of benefit to the AS/HFA student/trainee:-

- Accurate choice of courses based on assessment, transition planning, personal aspirations, special interests and goals;
- The introduction of school to college transition courses;
- Opportunities to take college modules of special interest whilst attending AS/HFA specific transition courses;
- Gradual introduction to college site/training centre and atmosphere ;
- College/training course attendance on planned full or part time basis with well planned and full timetable;
- Supervisory and monitoring structures.

Misunderstandings, which arise because of social and communication impairments, are regularly exacerbated by lack of awareness among staff of mainstream education/training institutes. There is an urgent need for the following measures to be implemented across the range of mainstream educational and vocational training settings:

- Staff information, advice, and guidance on AS/HFA;
- AS/HFA awareness training for frontline staff of FAS;
- Materials on identification and methods of support for students with AS/HFA;
- Awareness training for all staff through Disability Officers / named staff member of each educational/training institution (post leaving certificate, further/adult and higher education and vocational training);
- Scheme to train specialist support workers to organise peer and other supports (with the agreement of the person with AS/HFA);
- Links to share information and clarify roles of responsibility should be developed between disability officers, counselling staff, career guidance counsellors, vocational training staff, parents and local ASD intervention services;

- The DES and the Department of Health and Children should develop a one hour overview and information/awareness package on AS/HFA for distribution to vocational training staff, post secondary, further/adult and higher and vocational training/education institutes;
- Disability Officers, student counselling services staff and the named staff member with responsibility for individuals with AS/HFA in education/training institutes, should be placed on mailing lists for in-service training sessions, seminars and workshops held by ASPIRE, DHC, DES and related bodies;
- Introduction to the positive aspects of mentoring;
- Establishment of firm links with parents.

Submissions to the Task Force suggest that students with AS/HFA and their parents experience significant difficulties obtaining information regarding educational supports and assistance available post second level. The Task Force recommends, therefore, that the Department of Education issue a pamphlet outlining the range of educational assistance, disability funds, and supports available to persons with disabilities who wish to pursue Post Leaving Certificate, further education and third level courses.

Improvements in the participation and retention rates of students with AS/HFA in post secondary education/vocational training have been identified by the Task Force as an urgent priority, which should be addressed by flexible support structures and the allocation of additional resources to students with AS/HFA across the range of post secondary education/vocational training settings.

10.7.12 Continuing Education / Vocational Training/Supported Employment

Continuing education and vocational training for persons with ASDs may take place in a variety of locations. As stressed throughout this report, the principle of education in the least restrictive, age and ability appropriate environment should also be applied during late adolescence and adulthood. The suitability of placements should, therefore be identified through the independent multi-disciplinary post secondary education/vocational transition assessment procedure, and placements should not be based merely on 'local availability'. Differentiated training initiatives and support structures for individuals with autistic disorder and for AS/HFA need to be developed to address the differing needs within the autistic spectrum.

Sheltered day rehabilitative and vocational training initiatives for adolescents/adults with ASDs should ideally operate with specific objectives within a limited time frame, and should incorporate external monitoring and review procedures. This is important to ensure that stated objectives are adequately met and that the best interests of those with ASDs are served. Concerns have been expressed to the Task Force that some training initiatives appear to be somewhat 'open ended' and do not always have a clear end in sight. In such situations, goals and outcomes may be unclear. The Task Force considers that training should at all times, be purposeful, and lead to the

acquisition of educational/ vocational skills. All ASD initiatives for adults should include earned holiday time and pay for work when applicable. The list below is not exhaustive but reflects some of the continuing education/ supported employment options, which may be more appropriate for some people with ASDs who may require a supported or sheltered setting.

- supported employment initiatives
- AS/HFA specific vocational training initiatives
- specialised colleges of higher/further/adult education
- therapeutic work shops (autistic disorder)
- special needs classes in 3rd level, continuing education, community education or intellectual disabilities settings
- continuing education programmes
- intellectual disabilities settings (autistic disorder)
- programmes attached to residential services
- programmes in the individual's home

10.7.13 Preparation Strategies for Autistic Disorder

As outlined throughout this report, although there is considerable overlap in some of the impairments of ASDs, there are also distinct differences in terms of language and intellectual ability and dependency levels. Therefore the reader is cautioned to note that the support needs of persons with Autistic disorder and AS/HFA differ significantly. To address the educational and life needs of late adolescent/adults with autistic disorder in some of the above settings the following strategies and preparation will be needed; -

- advance autistic disorder awareness training for all staff, domestic, transport etc. as distinct from specialist supervisory, care, and training staff in adult centres and therapeutic workshops;
- autistic disorder awareness training for management, supervisors, co workers, in supported employment environments;
- autistic disorder awareness training for management, supervisors , co workers and staff in temporary and permanent work placements;
- autistic disorder training for all ancillary staff (domestic and transport) and participants in intellectual disability services.
- External social/community programmes for all individuals with autistic disorder in residential settings, with autistic awareness training for all associated staff and other participants;
- Ongoing traing and counselling in the home for parents/guardians/carers of persons with autistic disorder
- Reverse integration for leisure/social activities where the individual with autistic disorder for whatever reasonn (severity of disibility; long term illness etc.) is confined to a residential setting
- Links at all times with ASD intervention services.

10.7.14 Social Enterprise/Structured Employment:

This consists of employment in an enterprise establishment specifically for the employment of people with general disabilities, and is in receipt of special funding from the State. Workers are employees and in receipt of a wage. These enterprises are usually operated by voluntary bodies and may be initiated through the PEP scheme (pilot programme for the employment of people with disabilities). The aim is to determine the feasibility of establishing commercially viable enterprises, which employ a maximum of fifty per cent of people with disabilities. This scheme is funded by the Department of Trade, Enterprise and Employment.

Ideally, small job training teams could be placed in relevant settings within the community, so the actual work experience is taking place in a setting where the individuals with ASDs can be integrated with the general workforce for those portions of the work or training day that is relevant for them.

10.7.15 ASD Specific Regional Colleges

Some communities in the UK have established 'Colleges' specifically for students with ASDs. Some students attend full time, other attend part-time and are supported part-time in a local mainstream college, while others receive support in mainstream from the specialist college. Some places are residential and some are day courses. The specialist focus is primarily on the development of those skills, which are required to be successful in the third-level or continuing education setting. Additionally, a formal relationship is established to consult to the receiving institution to facilitate their understanding of how the disorder affects their student(s) with ASDs and how they might accommodate them. Issues as basic as the humming noise of the overhead projector causing the student with an ASD to leave the room are identified and considered beforehand.

The InterACT Centre (UK) is a non-residential further education college, which specialises in the education of people with autism and Asperger's Syndrome. The college is intended as an alternative for those who are not, as of yet, ready for the demands of local colleges. The learning is mostly practical and accredited learning includes: key skills, City and Guilds Certificates and the RSA National Skills Profile. Within the range of support available are: an understanding of adolescence, guidelines for behaviour, strategies for organising and planning, graduated supervision and tutorials and action planning. The Centre is fully accredited by the National Autistic Society's Autism Network Quality Audit Scheme.

Third-level and specialist colleges (e.g. hotel training and catering colleges, home economics colleges) etc. should begin to develop modules specifically for students with special needs.

10.7.16 Supported employment

Supported Employment initiatives operate by locating employment for individuals with disabilities in the open market. A range of support is available to both the employer and the employee. The supports include income support

payable to the employer for loss of productivity; capital grants are available to enable work-place adaptations to be made if necessary. Job coaches are employed to assist the employer and staff to develop an understanding of the difficulties and needs of the prospective employee in the workplace and to provide advice to the employer as required. The job coach also assists the prospective employee with initial training at the job location on a phased basis, or by providing confidential advice to assist in maintaining employment. The delivery of supported employment services is increasingly facilitated through the establishment of supported employment consortia consisting of organisations of and for persons with disabilities throughout the country.

10.7.17 Supported Employment: Asperger Syndrome

Supported employment for adults with Asperger syndrome first started in Ireland in 1998 through ASPIRE, when EU Horizon funding was provided for a 2-year (approx.) pilot project. A total of 21 people actively availed of the service during the 27 months of this project. The common characteristic amongst the clients was that few had held down jobs for longer than a few months prior to availing of the service. At the end of the project eleven people were in employment, of these five were in full-time employment, four in part-time employment and two were on Community Employment schemes. A further four were in training or further education, one had just finished a training course, four were not available for work due to illness or other reason and one transferred to a service.

During 2000 the service continued with temporary financial assistance from the East Coast Area Health Board. More recently this service has been mainstreamed and the Dublin South Supported Employment Initiative (funded by FAS) has overall responsibility for the service. At present 12 adults with Asperger syndrome are availing of the service. One parent recently wrote to the Job Coach *'He loves the job.... we cannot thank you enough for getting him the chance to prove he is capable of work...it has made a wonderful improvement to all our lives'*.

The Prospects Employment Consultancy (UK) model of supported employment is a scheme of the National Autistic Society (UK). It is contracted by the Department for Education and Employment and works in partnership with the Employers Forum on Disability. They operate a specialised employment consultancy service for people with autism and Asperger's Syndrome. Staff works closely with forward-looking employers to find real job opportunities for wages. The emphasis is on matching the individual's skills to the job, and Prospects staff provide the necessary consultancy to people with autism and Asperger's Syndrome and their employers to enable each individual to fulfil their potential and contribute to the success of their organisation .

The Task Force acknowledges the need for Asperger Syndrome specific and Autism specific supported employment schemes in Ireland and recommends that as an initial step toward the establishment of such services (based on sufficiency of numbers in each region),

- Supported Employment schemes should be developed to replicate the existing model (the Dublin South Supported Employment Initiative) with additional ancillary supports provided through the ASD intervention services.

or

- each ASD Health Board Intervention Service (or service provider with responsibility for late adolescents/adults with ASDs) should include a supported employment specialist/ ASD trained job coach as part of the core intervention team.

10.7.18 Community Employment (CE) Schemes:

Community employment schemes are the responsibility of the Department of Trade, Enterprise and Employment and are operated by FAS. These schemes cater to people with and without disabilities and were designed to combat long-term unemployment. The scheme consists of assistance from FAS to locate appropriate employment whether in the open market or by referral to a sheltered/supported position. Persons with disabilities that in the past were clients of the NRB now are directed to FAS.

10.7.19 Level 1r Training Programmes

This type of training programme provides activities and training in a sheltered environment and may be used in both residential and day service settings. Autism specific rural models include Dunfirth Farm in Kildare and Cloonmore Farm in Galway. However the majority of adolescents/adults with autistic disorder are placed in sheltered programmes administered by voluntary agencies for people with an intellectual disability. Level 1r Training courses vary in content and generally focus on general life skills as opposed to academic and vocational pursuits. Large sheltered workshop settings are outdated and have been highly discouraged in favour of smaller and more 'person centred' approach. Examples of existing level 1 courses and settings are:

- 'Tuiscent' is a two-year, level 1r, training programme, established by EVE Holdings and located in Dublin. It is currently the only late adolescent/adult training course in Ireland, specifically aimed at those with Asperger syndrome and high functioning autism who are not ready to enter mainstream education or work placements.
- Gheel Autism Services Ltd in Dublin, (Autistic Disorder-Specific), caters to 56 adolescence/adults in both day and residential care.
- Regional Health Board Level 1 rehabilitational training courses, which cater to a mixed clientele.

The absence of post secondary transition courses/dedicated training initiatives for persons with AS/HFA throughout the country has caused immense difficulties for many school leavers. Evidence to the Task Force suggests that existing level 1r training courses may not be the best option as, traditionally, such courses are not designed for persons with the unique impairments of AS/HFA but for an entirely different clientele, and therefore, they do not

adequately address the social and communication difficulties experienced by this group. The training needs of persons with AS/HFA have been outlined throughout this chapter and merit serious attention. Clearly, there is a need for dedicated provision to meet the needs of late adolescents/adults with AS/HFA who may not be ready for mainstream options. There is a need to develop AS/HFA specific initiatives, which would ideally incorporate links with local colleges, and the work place, whilst addressing core social understanding /communication skills in conjunction with career guidance and vocational skills.

10.7.20 Rural Communities

Autism specific rural communities are also a viable option for some adults with ASDs. Irish models include Dunfirth Farm in Kildare and Cloonmore Farm in Galway. Dunfirth Farm, which operates under the auspices of the Irish Society for Autism provides skill, based training to 32 adults with Autistic Disorder and 3-4 adults with AS/HFA. This ASD mix reflects the current shortage of provision on a national basis, rather than management policy, as health board referrals for the placement of individuals with more severe levels of disability tend to take precedence over the those who are high functioning. The project "Train Autism" provides people with a range of skills to enable each individual to contribute to his/her own development by participating in all aspects of rural life to the limit within his/her potential. Support plans are, therefore tailored to the needs of each individual. Modules include self-expression, home making, relaxation, leisure, and work skills. This project is life long.

10.7.21 Structures

The remit of the proposed Special Needs Organisers (SNO) would be to work in collaboration with ASD Intervention Service Co-ordinators, to develop, resource, support and evaluate the needed educational supports, programmes and services mentioned herein. The SNO would maintain close links with his/her counterparts at the secondary and level and VEC Adult Education Officers to insure proper transitioning procedures.

The Departments of Education, Health, and Trade, Enterprise and Employment should adopt a co-ordinated approach to meeting the educational, social, therapeutic and accommodation needs of adolescents/adults with ASDs.

The role of ASD intervention coordinators should include close collaboration with the proposed regional Special Needs Organiser, to develop and sustain links with the proposed AS/HFA dedicated training initiatives and vocational training institutes (e.g. FAS, CERT, etc..) and with further and third level institutions and colleges.

10.7.22 In Summary

To begin to meet the needs of adolescents/adults with ASDs in Ireland, education/vocational training provision should proceed on the basis of:

- A statutory right to appropriate ongoing education according to individual need;
- ASD adult and family support plan, statutory;
- protective and proactive strategies based on individual presentation;
- access to the support of a mentor/key worker in all education and training settings;
- meaningful leisure and social opportunities with a particular focus on addressing social interactional difficulties within activity oriented groups;
- therapeutic supports. e.g. counselling, speech and language therapy, occupational therapy, behavioural supports;
- Differentiated AS/HFA and Autistic Disorder specific respite and residential options appropriate to individual presentation.

Curriculum components may include:

- Professional and academic courses with support, for the more able;
- The development of academic potential;
- Functional and work-related development;
- Vocational, work and enterprise skills;
- Social communication skills;
- Self-care/self-sufficiency, including making informed choices;
- Independent Living skills;
- Personal and interpersonal relationship skills;
- Computer/IT skills;
- Inclusive and independent recreation and leisure skills;
- Arts/Culture participation, appreciation and enjoyment.
- The use of assistive technology
- Interviewing skills
- Coping strategies/stress management
- Job retention skills
- Role and duties of employment/employee
- Relationships with co-workers
- Organising of non-working periods

The Educational/Vocational Training Statement should address the:

- educational needs of the person (curriculum);
- desired outcome;
- best possible and appropriate methods;
- environment or setting for each structured learning opportunity;
- specialist staff required;
- frequency of evaluation;
- other identified issues.

The ASD Adult and Family Support Plans should be co-ordinated with the Educational/Vocational Training statement and further address:

- Accommodation/residential and respite needs
- educational and occupational guidance and counselling
- social needs
- therapeutic needs
- mental health needs

Mainstream accommodations:

- Legal advice for prospective students;
- Provision of personal assistants;
- Befrienders/mentors/advocates;
- Transport arrangements;
- Accommodation (sheltered, semi-sheltered & open);
- Grants for courses;
- Extra tuition;
- Counselling & therapeutic support;
- Leisure opportunities;
- Opportunities to participate in social skills/understanding groups;
- Provision of material aid to support learning (e.g. computers, written lecture notes etc.);
- Specialist support workers;
- Funding attached to the individual (as opposed to services);
- On-going support with independent living, communication, social understanding/skills groups, advice, guidance, and personal safety issues (through collaboration with local ASD intervention services).

The following strategies may be of benefit to the AS/HFA student:-

- Accurate choice of courses based on assessment, transition planning, personal aspirations, special interests and goals;
- The introduction of school to college transition courses;
- Opportunities to take college modules of special interest whilst attending AS/HFA specific transition courses;
- Gradual introduction to college site and atmosphere ;
- College attendance on planned full or part time basis with well planned and full timetable;
- Supervisory and monitoring structures.
-

In mainstream education/vocational training settings there is a need for:

- Staff information, advice, and guidance on AS/HFA;
- AS/HFA awareness training for frontline staff of FAS;

- Materials on identification and methods of support for students with AS/HFA;
- Awareness training for all staff through Disability Officers / named staff member of each educational/vocational training institution (post leaving certificate, further and third level education and vocational training);
- Scheme to train specialist support workers to organise peer and other supports (with the agreement of the person with AS/HFA);
- Links to share information and clarify roles of responsibility should be developed between disability officers, counselling staff, career guidance counsellors, vocational training staff, parents and local ASD intervention services;
- The Departments of Education/Health should develop a one hour overview and information/awareness package on AS/HFA for distribution to post secondary, further and third level education and vocational training institutes;
- Disability Officers, student counselling services staff and the named staff member with responsibility for individuals with AS/HFA in education/training institutes, should be placed on mailing lists for in-service training sessions, seminars and workshops held by ASPIRE, The Departments of Health and Education and related bodies;
- Introduction to the positive aspects of mentoring;
- Establishment of firm links with parents.

To address the educational and life needs of late adolescenta/adults with autistic disorder the following strategies and preparation will be needed; -

- advance autistic disorder awareness training for all staff, domestic, transport etc. as distinct from specialist supervisory, care, and training staff in adult centres and therapeutic workshops;
- autistic disorder awareness training for management, supervisors, co workers, in supported employment environments;
- autistic disorder awareness training for management, supervisors , co workers and staff in temporary and permanent work placements;
- autistic disorder training for all ancillary staff (domestic and transport) and participants in intellectual disability services.
- external social/community programmes for all individuals with autistic disorder in residential settings, with autistic awareness training for all associated staff and other participants;
- ongoing training and counselling in the home for parents/guardians/carers of persons with autistic disorder
- Reverse integration for leisure/social activities where the individual with autistic disorder for whatever reasonn (severity of disability; long term illness etc.) is confined to a residential setting
- Links at all times with ASD intervention services.

11. Recommendations

The Task Force Recommends:

1. that joint interdepartmental policy be developed to ensure the smooth planning and delivery of a continuum of multi- departmental support services to meet the education, training, , supported employment, intervention, accommodation and social needs of late adolescent/adults with ASDs as outlined throughout this chapter;
2. that services for persons with ASDs proceed on a basis of partnership between the Departments of Health and Children, Trade, Enterprise and Employment, Social, Community and Family Affairs, Finance, and Education and Science;
3. that improvements in the participation, retention and completion rates of students with AS / HFA in post leaving certificate, further, and third level education courses be targeted as an urgent priority; that this priority be addressed by the allocation of additional resources and flexible support structures (as outlined at 10.7.11) across the range of post secondary mainstream education settings;
4. that the concept of *lifelong learning* be implemented in practice through the availability of educational support in *the least restrictive environment* throughout the lives of persons with ASDs;
5. that funding be attached to the individual (transport, accommodation, course fees,) for persons with AS/HFA who participate in mainstream education/vocational training and are, therefore outside the remit of dedicated service provision;
6. that the educational/vocational training needs of adolescents/adults with ASDs be addressed through a Statutory Statement of Needs and a Statutory ASD Adult & Family Support Plan;
7. that compensatory vocational training and continuing educational initiatives, and interim measures be established to meet the education and training needs of persons with ASDs who have been excluded, or dropped out of the education system due to lack of support;
8. that all school leavers with ASDs be provided with flexible support and adequate opportunities to participate in age and ability appropriate education / training and supported employment options, as identified by the transition assessment process, and outlined at 10.7.22 of this chapter;
9. that Post Leaving Certificate, Further/Adult Education and Third-level student support schemes for persons with AS/ HFA be implemented throughout the country on a regional basis; that the Department of Education issue an information pamphlet outlining the range of

entitlements (e.g. educational assistance, disability funds, and supports) available to persons with disabilities who wish to pursue Post Leaving Certificate, further/adult and third level courses;

10. that AS/HFA specific Counselling Services be developed as a matter of urgency in all further/adult and higher educational institutions;
11. that AS/HFA specific Counselling services be developed as a matter of urgency through the ASD intervention services, for late adolescents/adults with an ASD who are outside the education system and the remit of other designated service provision.
12. that immediate steps be taken to identify and deliver appropriate transition and on-going post-secondary support to those people with ASDs who are in mainstream education/vocational training and outside the provision of dedicated service providers;
13. that the use of Assistive Technology in supporting learning be facilitated and encouraged; that grants for computers be forthcoming as there is evidence that many of those with AS / HFA find this medium of communication beneficial;
14. that the Department of Education and Science and the Department of Health and Children develop a one hour overview and information/awareness package on AS/HFA for distribution to post secondary, further/adult and third level and vocational training institutes;
15. that dedicated training provision to meet the needs of late adolescents/adults with AS/HFA be developed by the Departments of Health and Children, Education and Science and Trade, Enterprise and Employment; that such AS/HFA specific initiatives, would ideally incorporate links with local colleges, and the work place, while addressing core social understanding /communication skills in conjunction with career guidance and vocational skills;
16. that sheltered day rehabilitative and vocational training initiatives for adolescents/adults with ASDs should ideally operate with specific objectives within a limited time frame, and should incorporate external monitoring and review procedures;
17. that Supported Employment schemes be developed **through the collaboration of the Departments of Trade, Enterprise, and Employment, Education and Science and Health and Children** on a National basis to replicate the existing Asperger Syndrome model (the Dublin South Supported Employment Initiative); that additional ancillary supports be provided through the ASD intervention services or, based on sufficiency of numbers, that each ASD Health Board Intervention Service (or service provider with responsibility for late

adolescents/adults with ASDs) include a supported employment specialist/ ASD trained job coach as part of the core intervention team.

18. that sheltered housing and supported/semi-supported accommodation in the community be provided in conjunction with out-reach schemes which enable people with ASDs to live in homes of their own if they so choose;
19. that the role of ASD intervention coordinators include close collaboration with the proposed regional Special Needs Organisers and VEC Adult Education Officers, to develop and sustain links with the proposed AS/HFA dedicated training initiatives and vocational training provision (e.g. FAS, CERT, etc..) and further/adult and third level institutions and colleges.
20. that, in situations where existing further vocational or third level programmes prove to be too academically oriented for lower-functioning pupils, FETAC (Further Education and Training Awards Council) provide appropriate alternatives.

CHAPTER 11

CLINICAL AND SUPPORT SERVICES

This Chapter will reflect on the difficulties associated with the current level and quality of clinical and support services for ASD children and their families in Ireland, consider the types of services required for effective support, and make recommendations to address the inadequacies of the current situation. A large number of the submissions to this Task Force (forty-nine) included comments on and recommendations for clinical and therapeutic input and family support needs. This reflects the perceived importance of such services to the education of children with ASDs *within* ASD educational services.

11.1 BACKGROUND

In August of 1994, a commissioned Report entitled “*Services for Persons with Autism*” was presented to the Minister for Health. Emphasis was made on the need for (p. 4) early diagnosis, a paediatric assessment; (p. 5) provision of mainstream and specialised education including an individual programme plan based on a multidisciplinary assessment, support from a variety of consultants; (p. 6) regular speech and occupational therapy services, support for the family including in-home support and respite care, the establishment of staff training protocols; (p. 7) home-based programmes; (p. 8) small classes with ample space by age three with a maximum ratio of six children per class with a teacher *and* a special needs assistant; and (p. 10) extra resources to maintain community integration during adolescence. The report suggested that (p. 8) the Department review the advisability of establishing a National Diagnostic Centre; (p. 12) consider identifying a specific member of staff to co-ordinate services for autism; and (p. 13) establish a database on persons with autism. On p. 14 a need for epidemiological research on outcome in autism was highlighted and a summary statement advised that:

Regional diagnostic clinics should be established to provide a third-level diagnostic team and to act as a resource centre providing teaching programmes for staff in a variety of disciplines.

The SERC Report (1994), recommended that:

All students with special support needs, in ordinary and special schools, should have ready access to such additional support services and personnel, including speech-, physio- and occupational therapists, as their assessed needs may require from time to time.

The Department of Health and Children, and the Health Boards, should take appropriate and urgent action in relation to the shortage of speech therapists. Speech therapists (on a full- or part-time basis, dependent on the numbers of pupils requiring therapeutic interventions) should also be made available in schools and other educational settings by the Department of Education and Science. This would be in line with the provisions of the 1998 Education Act.

The idea that service provision may be made by different government departments is not new. What is necessary in the view of the Task Force, is the need for Government Departments, particularly the Department of Education and Science and the Department of Health and Children, to clarify and co-ordinate the delivery of services in a collaborative manner. The Task Force contend that Health Boards should audit and clarify further what services they are each responsible for, to ensure that parents and professionals are clear as to what services they can expect, from whom, and what services *should* be in place to address successfully the health and educational needs of their children/young adults.

11.1.1 PRESENT STATUS

In the Terms of Reference set by the Minister for Education, the Task Force was asked to consider issues not exclusively related to the education of ASD children, but to include support services as part of the brief. The submissions received by the Task Force were heavily weighted with such issues. It is impossible to discuss educational provision without being acutely aware of the multitude of other significant needs of ASD children, adolescents, adults and their families. To date, these collateral needs have been inadequately provided for in the vast majority of cases, although a small number of students, i.e. some of those in a residential and/or special schools, are considered to have good back-up support in most cases. As programmes expanded over the past three years and community-based classes in mainstream schools have become more favoured than special school provision, the demands on all back-up services have far outstripped the supply. One mother wrote:

We feel that the absence of speech therapy has greatly impeded our son's development. In eleven years of schooling he has only had about one year of speech therapy. This was sporadic and done on a part-time basis. It has been hopelessly inadequate for a child who still CANNOT communicate.

A group of mothers requested that all children with an ASD be eligible for Medical Cards:

Our children often suffer from recurrent ear infections, bowel problems etc. Because they often cannot communicate what or where is the problem there are many 'just in case' visits to the doctor.

11.1.2

As with the Department of Education and Science, the Department of Health and Children and the regional Health Boards grossly underestimated both the numbers of children with ASDs and the types and degree of support that would be required. Until very recently, children with ASDs were not designated as a special group, but included in either Mental Handicap or Child Psychiatry programmes. There were very few programmes in the health services which are specific to an autistic spectrum disorder. St. Paul's in Beaumont, Dublin and Beechpark, Dublin, had a restricted number of residential places and very limited respite available. These programmes did, however, provide nursing care, a psychiatrist, a psychologist, a speech and language therapist, and a social worker. St. Paul's also has a Play Therapist, and is linked with the Mater Hospital Child Guidance team, and Beechpark added an Occupational Therapist to their team approximately three years ago and, more recently, "Project Workers" (ABA Specialists) and a part-time Dietician to their Outreach teams. In other areas of the country, non-governmental agencies typically included some children with ASDs in their programmes, but did not provide programmes for children with Asperger's Syndrome/High Functioning Autism. The children with autistic disorder and their families received services primarily from agencies which provide services for children with a general learning disability. Higher functioning children attended their local Child and Family Centre. For example, KARE in County Kildare has had a long-standing special class for children with autistic disorder within their service for the profoundly handicapped. Higher functioning children attended their local Child and Family Centre. The difficulties that routinely arise for young adolescents and adults with AS/HFA who are no longer eligible for the services of the Child and Family Centres and are without appropriate dedicated service provision is a cause of serious concern to the Task Force. As specified under 11.1 above, in 1994 it was recommended that each of the Health Boards develop their own specialist services for this population. This development, for a variety of reasons, is still at an early stage of development and reflects the lack of strategic leadership or dedicated ASD services within the Health Boards. Even now, only a few of the health boards have an administrative post solely to develop their ASD services, and the Department of Health and Children itself relegates this to their Disabilities Officer who is spread across a wide range of disabilities, thus faced with an impossible task. Funding allocated to services for children with an ASD by the Department of Health and Children has increased consistently but, given that the baseline was at or near zero, the funding has been insufficient to address the demands. **The Department of Health and Children** has been slow to recognise this.

A further and core difficulty is the insufficient numbers of clinicians available to fill current, let alone, additional posts. There is an acute shortage of appropriately qualified clinical support professionals in the Republic of Ireland to meet the needs of children with disabilities, including those with ASDs.

11.1.3

Considerable and lengthy attention was paid in submissions from parents to the Task Force to the importance of making counselling available at the time of diagnosis and at any other times when the parents and siblings feel they require it. Adolescents and young adults with AS/HFA were the focus of particular attention in this regard. The following extracts were typical:

Currently there is little or no counselling available to parents of autistic children. I'm sure you can imagine the devastation felt by parents of newly diagnosed children. It is an extremely stressful time and we feel that there should be counselling available to parents as a matter of course and that counselling should be available on an ongoing basis to all those parents who need it.

Counselling needs to be made available to parents and siblings. Above all counselling needs to be made available to the person with ASD. Opening some of the unfilled posts to Counselling Psychologists and Psychotherapists could at least begin to meet the counselling needs so strongly expressed.

Other factors that need to be remedied are the high case loads and poor conditions experienced by many clinical staff. These militate against effective service delivery. There is also a need for increased opportunities to be provided for clinical support staff to avail of continuing education on issues specific to children and students with an ASD.

11.1.4

Some Health Boards delegate clinical services to non-governmental service providers who cater to those with a general learning disability. This limits the service to children with a mental handicap, thus excluding children with ASDs who have borderline or cognitive ability average in the average range, e.g. children with AS/HFA. Non-governmental service providers form a very significant component of the support service structure. In many areas these organisations have been the sole providers of essential service and supports. Nevertheless, numerous Task Force submissions from parents highlight their experiences with non-governmental service providers whom they found generally unresponsive and who, at times, actually impeded their access to needed services. The impression from these submissions is (a) that some of the non-governmental service providers may have not moved forward and incorporated up to date knowledge and practices, and (b) that there may not have been sufficient transparency with regard to expenditure by the Health Boards, and that they may have spent their funds in ways that presented a 'good face', but did not contribute to necessary comprehensive provision for persons with ASDs and their families. The need for transparency and accountability was prevalent in the submissions.

While many professionals provide an excellent service, the attitude of some professionals was cited in submissions as a source of distress. One advocacy organisation stated:

The parents of Autistic children are frequently treated with indifference, even contempt, by professionals and administrators, while they are left to carry the burden of caring for their children virtually alone.

Similarly, the mother of a daughter with Asperger's Syndrome wrote:

You see the professionals always think that they know best, not the parents. It still amazes me why my feelings and concerns were not listened to.

11.1.5 Residential/Respite/Home Support Services

Correspondence received by the Task Force from the Department of Health and Children (April 2001) indicates that there are recent and on-going efforts to remedy the deficiencies noted above and to provide residential, respite and home support services. The following lengthy quotations from this communication outline their intentions:

... The Department has identified the ongoing enhancement of the respite services as a key priority and additional funding has been specifically targeted in recent years for the provision of new respite places. In 2001, in addition to funding to put in place new respite places, each health board region has been allocated funding to provide 4 high support respite places as part of the overall enhancement of the services required to support persons with autism and those with an intellectual disability who require such support.

The development of a range of new residential facilities for persons with autism is also an integral part of the ongoing development of the services.

11.1.5.2 Resources and Challenges Facing Services

Between 1998 and 2000 additional funding amounting to £5m was provided specifically to enhance the assessment, diagnostic, early intervention and other health related support services for children with autism. A further £3m has been provided in 2001, with a full year cost of £3.5m in 2002 to further enhance these services for children with autism and also for those with an intellectual

disability. In addition respite, residential and day services for this population group as a whole have also been expanded.

However, given the increased numbers of children being diagnosed with autism and the expanding range of educational settings in which they are and will continue to be placed, there is a need for continued investment in the support services which they and their families require.

11.1.5.3 Recruitment and Retention Difficulties

On receipt of the report of the Expert Group on allied health professionals last year, the Department immediately began to implement the recommendations made for the various professions covered by the report. This included increasing, where possible, the number of training places available in October 2000.

The Department commissioned a workforce planning survey to report on the prospective supply and demand for physiotherapists, occupational therapists and speech and language therapists between now and 2015. This report, which was prepared by Peter Bacon Associates, has just been presented to the Department and is being considered by the Minister. The report addresses the number of training places required for these professions. A similar exercise in relation to dieticians will take place over the coming months. Terms of reference are currently being agreed.

The current therapy training providers have been asked to examine the establishment of a “fast track” degree programme in physiotherapy, occupational therapy and speech and language therapy for those who already have a related degree qualification. This will allow for these graduates to complete their training in approximately two to two-and-a half years, instead of the usual four years.

New grades of Clinical Specialist Posts for the therapy grades and a Senior Social Worker Practitioner have been created to allow for career progression for those who do not want to move into management. This development should help in the retention of key senior staff and allow for expertise to remain within the professions. The National Social Work Qualifications Board published a report in July 2000 “Social Work Posts in Ireland”, which flagged the creation of 200 new posts over the next two years. The Board has since recommended the creation of sixty-eight additional training places each year for the next four years. Talks are ongoing with the Higher Education Authority and the

Department of Education and Science with the aim of providing these places as quickly as possible. In parallel, a survey of all employers has taken place to establish how the required additional practice placement places can be made available. To assist with the increase in practice placement opportunities needed, a new grade of Clinical Placement Co-ordinator has been created for each of the therapy professions and for social work. This person will co-ordinate placements within geographic areas, and at national level, co-ordinate with the training colleges.

A complete review of training places available to childcare workers is underway under the auspices of the Expert Group on ChildCare Workers. It will address the suitability of training, as well as looking at the appropriateness of the number of graduates being produced.

A Review of Psychology Services in the health boards is almost complete. Thirty additional post-graduate training places were created from October 2000, with proposals to create further places from October 2001. Universities outside the current providers are keen to develop post-graduate training programmes and it is hoped that further training places can be provided.

The Expert Group recommended the introduction of therapy assistants, who, following the completion of a suitably accredited training programme, would work under the supervision of therapists and provide very necessary practical support for them in the delivery of the services. The Department welcomes this recommendation and would wish to see it implemented as quickly as possible.

The health boards and specialist service providers are working together to ensure that the maximum benefit is achieved from recruitment drives for both the autism and intellectual disability services. The Department of Health and Children is also assisting, where necessary, in relation to areas such as the recognition of qualifications of professionals recruited from abroad and liaising with other Government Departments in respect of the granting of work permits etc. (Communication from the Department of Health and Children to the Task Force, April 2001)

The Task Force recommends that the Department of Health and Children implements the initiatives identified within the Report of the Expert Group on Allied Health Professionals. The Task Force further recommends that the Health Boards collaborate with the Department of Education and Science to ensure the

provision which each contributes to the overall level of provision for all individuals with ASDs.

11.2 Psychological Support Service

As regards the provision of National Educational Psychological Service psychologists, in an oral presentation to the INTO Congress in Tralee on 17 April 2001, the Minister for Education made the following statement:

This school year we have increased the number of (NEPS) psychologists by fifty-eight to one hundred and I will recruit a further twenty-eight before next Christmas. This will bring the total to 128, and we will bring the total further to 200 as soon as possible.

The Task Force accordingly, recommends that the Department of Education and Science take every possible initiative to move to the appointment of 200 psychologists at the earliest possible time. As noted in other sections of this report, in order to offer an useful educational assessment and planning service to students with an ASD, or indeed any students with significant handicaps, the eventual number of psychologists will need to rise significantly above that included in the NEPS Development Plan.

11.2.1. Regional ASD Teams

The Task Force considers that the Department of Health and Children and Health Boards' intention to establish local ASD teams will be a valuable intervention which should provide more effective services. The teams should endeavour to secure:

- child and adult psychiatrists, as consultants to the team, particularly to support those young persons with Asperger's Syndrome at difficult times during adolescence when they experience significant emotional difficulties; and to all with an ASD when they are experiencing significant emotional and/or behavioural difficulties; child and adult psychiatrists have specialised medical training and this should be reflected in the role that they play in relation to the teams, maximising their specialist support;
- a range of medical services, including access to genetic testing and hearing evaluation, visual examinations, and where indicated, gastrointestinal and dietary consultations, within a thorough developmental paediatric assessment;

- provision of information leaflets which indicate to parents the ways to access services and service personnel e.g. doctors, dentists or consultants, who are informed and sensitive to their children's needs;
- respite care which is specific and distinct to the various needs of persons with Autistic disorder and Asperger's Syndrome;
- effective training for staff across the services to deal adequately with persons with ASDs;

11.3 NECESSARY SUPPORTS

This section will focus on the needs of the person with an ASD and their family. Each child, family and classroom will have need for their own unique menu of supports. Parents, in particular, are acutely aware of their child's and family's needs. The submissions indicated an urgent need for the provision of a range of therapies, for example, speech, occupational, sensory integration, and behavioural. Parents have learned from the international experience and research which is now readily available and accessible to them that such therapies are critical to their child's future, that they can reduce the adverse effects of the ASD, and open their child to a potentially higher level of general functioning.

11.3.1 Medical Advice

Submissions to the Task Force indicated that advice on the medical and dietary aspects of the disorder is often requested from professionals and statutory agencies, but is rarely available through any but the parents' own sources and resources. There is anecdotal evidence that some children's behaviour improves if on casein and gluten free diets. It is also possible that some children may benefit from B6 and magnesium therapy. There are numerous medical issues and treatments that become associated with ASDs from time to time, Secretin being a recent example. These matters require further investigation. Consultant Psychiatrists in the ASD service could take a lead role in this regard.

11.3.2 Information

Perhaps one of the greatest sources of stress to parents, from pre-diagnosis to adulthood, is lack of information (Murray 2000; EHRA 2001). A total of seventy-five per cent of the respondents in the Murray (2000) study stated that this was their main problem at the time of diagnosis. Some seventy-one per cent indicated they wanted information on treatment options and medical advice. Equally important is the need for parent training so that they and at times, siblings can be co-facilitators in addressing the ASD child's needs. The need to make

information easily accessible to parents was raised frequently in the submissions and is clearly evident in the following examples:

There is need for the provision of accurate information to parents before and after diagnosis. Counselling services should be available to parents if required. Professional assistance should be provided to explore the options for the education of the child in the local area. Practical support should be afforded to the parents to encourage, stimulate and foster the child's own development within the home and amongst his/her siblings.

One organisation highlighted a possible role for the Internet here:

Information should be made more accessible, e.g. via the Internet, thereby making it available to all those working and living with autism, who have access to a computer. As parents are the primary educators of children, a comprehensive information package should be available to them from the health boards, Departments of Health [and Children] and Education [and Science]. If you educate the parents you are half way there.

Another parent group suggested:

Help Lines/Responses Units - with all the necessary back up to cope with problems/emergencies must be provided on a 24-hour basis. Parents and carers must be provided with immediate Medical, Advisory and Supportive services.

The Task Force recommends that information on treatment options and medical advice be made available to parents by relevant professionals and that adequate information and advice is made available to parents to enable them to make informed choices about how to proceed on accessing the support they require, or which has been recommended, for their children.

11.3.3 Respite

The negative impact on family functioning, on parents and siblings, is well documented both in the literature and in the Task Force submissions received. The stress experienced by families with a member with a disorder on the autistic spectrum permeated virtually all of the submissions, especially those from parents and parent's groups. One parent argued that a whole package of supports is essential to enable parents to cope:

Nothing prepares a parent for the diagnosis of Autism and from that moment onwards every aspect of family life is affected by a

multitude of problems. From the outset, parents need counselling, guidance, support and home help and most of all RESPITE to enable them to cope and survive. The present system does not support parents in their many crises and survival by 'trial and error' results in parents despairing and in even more isolation for their child.

Practical support is very thin on the ground, and in great demand. Even something that is typically quite simple, such as a haircut, or visit to MacDonald's, can cause a very high level of stress in these families. Normal outings can be a nightmare and result in progressively increasing social isolation for the family. Society must find a way to share such responsibilities with these families. It must be acknowledged that, as difficult as it is for any family to cope with a child with special needs, most of those dealing with a child/young person with an ASD have an even greater level of stress and challenge.

Article 4.2.1 of the Constitution declares:

The State acknowledges that the primary and natural educator of the child is the family, and guarantees to respect the inalienable right and duty of Parents.

For a family with an ASD member, along with this 'duty' comes an extraordinary, and life-long, degree of stress. This is borne out by the large number of submissions to the Task Force, for example:

Coping with an autistic child devastates normal family life. Daily activities, such as eating, shopping, sleeping etc., have to revolve around this child. Siblings have a right to their own space and time, but catering to their needs can be very limited as the autistic child gets preference. The home life of siblings is difficult and demanding, so they too need support and information. Parents are often faced with difficult decisions to sustain fairness to all children when dealing with situations caused by the disability of the autistic child.

Many parents expressed significant concern for the brothers and sisters of the child with an ASD. These children have to cope with their unique home life, exhausted parents, and the very different behaviours of their brother or sister, which in some cases, can be very upsetting, restricting, and/or intrusive.

The urgent need for respite services was mentioned in approximately twenty-five per cent of Task Force submissions. There was absolute consensus among all those who mentioned respite care that there is a need to develop such services around the country, as living with a person with a disorder on the autistic

spectrum can be very demanding and exhausting. This point was well made by one mother who wrote as follows:

Respite should be available, in all its forms, as a right. Rearing an autistic child is very demanding and extremely stressful for the whole family. Erratic sleep patterns and the behavioural problems of the autistic child can cause great distress.

The submission from an organisation stressed:

The highest priority should be given to home support and respite care with need as the only criterion for its provision.

Another parent stated:

Respite is a lifeline for parents and siblings. Every child has a right to safe, reliable and supportive care. This respite should suit the parents needs and be available as required. It should be provided in comfortable and bright surroundings and be interesting and stimulating.

Home supports, out of home respite and, in exceptional cases, residential care must be offered from a very early age and continue through adulthood. This is not because parents do not want to have their child in their home, but for many families they find that they just cannot cope 365 days and nights a year. Their children do not visit their aunts and grannies for overnights, or spend nights at friends' houses as typically developing children do. It is even difficult and in some cases impossible to find a childminder for the parents to go out on their own now and then. One father described how the entire situation surrounding his autistic son, one of six young children, became incredibly difficult when his wife was diagnosed as having a serious malignant illness. He wrote of the trauma associated with taking the decision to place their son, aged fourteen, in residential care:

Our parting with B., whom we loved so much, will be etched in my mind forever as the most shattering, traumatic and emotionally disturbing event in my life. However, we were kindly received by the doctor in charge and the staff.

Children with high functioning autism or Asperger's Syndrome must also have access to respite resources so that they can be accompanied to age-appropriate activities in the community and have the opportunity to go on holidays and otherwise spend some time away from their family. This is important for the children/young adults themselves, as well as for their parents and siblings. They will need to be accommodated in programmes distinct from the more autistic or delayed children, to meet their unique needs and maximise 'normalisation'.

Residential support and options for these older teens, young adults and adults must also be developed.

For ageing parents there is the stress of worrying what adulthood has in store for their sons/daughters when they themselves are no longer able to care for them. They spend their lifetime as carers, advocates, lobbyists, and activists with little time for lives of their own. They are not able, as most other parents can, to look forward to some independence and peace of mind in retirement and old age. A full range of age, **adaptive functioning and ability** appropriate residential options, as well as respite, is necessary, ranging from fully supported part time, to partially independent full time out-of-the-family home residences.

The Task Force is aware that there are quality as well as quantity issues in the matter of respite and residential care. For this very special group of children, teenagers and adults simple 'minding' in respite or residential situations will not be adequate. Respite and residential care must involve well-planned and structured, high quality programmes and activities, appropriate to the needs of children and young people with an ASD.

11.3.4 In-school Support Services

Teachers of children/adolescents with ASDs need the support of services including speech and language, occupational and physio-therapies, and behavioural specialists to enhance the work of the classroom. The Task Force stress the need to ensure that such services, with appropriate intensity and frequency, are available and are integral to the overall Individual Educational Plan of the child. To this endeavour the Task Force considers the need for the Department of Education and Science and the Health Boards to co-ordinate their provision in order to address the current deficiencies and to establish adequate levels of staffing across the country to match the increasing numbers of individuals identified with ASDs who need therapy support services.

11.3.4 Good Practice in Support and Information Provision

In order to develop effective clinical support systems parents should be provided with information which indicates clearly:

- the procedures and protocols which direct ASD services;
- the range of services including diagnostic, residential, respite and social services available;
- the level of parental involvement and support, including parent training programmes;

- appeals procedures for parents to follow when there is disagreement;
- inter-agency links, particularly between the Department of Education and Science, the Department of Health and Children and the Department of Trade, Enterprise and Employment detailing the responsibilities of each service in respect of provision;
- links establishing the working arrangements between the Health Board ASD co-ordinator and the proposed Department of Education and Science Special Needs Organiser.

Further, the Health Boards should provide:

- a multidisciplinary diagnosis/assessment of the individual with an Autistic Spectrum Disorder;
- a mandatory Child/Adult and Family Support Plan, detailing the individual level of medical, clinical and practical services necessary to address the individual's needs and indicating service responsibility.

11.4 Recommendations

The Task Force recommends:

1. that the Interdepartmental Co-ordinating Committee, already established to clarify and define the distinct roles of each Department, identify and ensure delivery of a range of ASD services, and secure sufficiency of staffing at local and national level to meet the expected needs of persons with ASDs in Ireland;
2. that speech therapists and other support services as required are made available in schools and other educational settings by the Department of Education and Science;
3. that the Department of Health and Children implements the initiatives identified within the Report of the Expert Group on Allied Health Professionals;
4. that local committees co-ordinated by the Health Board ASD Co-ordinators and the proposed Department of Education and Science Special Education Needs Organisers be established and liaise formally to secure

the smooth management and administration of ASD health and education services at local level;

5. that independent regional diagnostic assessment and intervention services for ASDs be set up in each Health Board area; that where the required clinicians are not available on the team, full effort should be made to contract with local private practitioners;
6. that an ASD specific service be set up in all Health Board areas to ensure that all persons with an ASD across the range of educational settings should have access to all appropriate clinical and medical assessments/services, from the point of referral or diagnosis, to meet their needs;
7. that the Health Board ASD specific service teams devise the statutory Child/Adult and Family Support Plan for the person with an ASD and his/her family;
8. that automatic entitlement to a medical card should follow diagnosis of an ASD;
9. that information on treatment options and medical advice be made available to parents by relevant professionals; and that such information and advice reflect international standards of good practice and be adequate to enable parents to make informed choices about how to proceed on accessing the support they require, or which has been recommended, for their children;
10. that respite care (and, in exceptional circumstances for those who require it, residential care) be provided for families as their need arises, and that such respite and residential care be characterised by well-planned and structured, high quality, age and autistic disorder and AS/HFA differentiated programmes and activities;
11. That the support needs of adolescents and adults with AS/HFA be coordinated by the Department of Health and Children, Education and Science and Trade, Enterprise and Employment and that such services be delivered through AS/HFA dedicated service providers at local level.

CHAPTER 12

EDUCATION AND TRAINING FOR TEACHERS, OTHER PROFESSIONALS AND SUPPORT STAFF

12.1 INTRODUCTION

The issue of the education and training of teachers, other professionals and support staff is fundamental to the success of our proposals on the reform of the education of children and adults with ASDs. Teaching methods and standards are very closely linked to learning outcomes for all children. There has long been an awareness of this in educational policy. For example, it formed the basis of the introduction of the “child-centred” primary curriculum in 1971. Child-centredness has continued to be the cornerstone of the revised primary curriculum of 1999. The second level curriculum is a great deal more subject centred, although recent years have seen a number of developments such as new curricula and programmes in which personal and social issues may be explored, and the growth of pastoral systems in schools. From the point of view of pupils with ASDs and other disabilities, there is a need to continually reassess teaching methods and standards in the light of research and international findings and guidelines on good practice.

It is also essential that other professionals and support staff receive adequate education and training relating to the nature of the distinct disorders which occur on the autistic spectrum and to procedures and intervention strategies, as indicated. Such professionals would include psychologists, speech and language therapists, occupational and other therapists, and medical personnel. It is also essential that special needs and childcare assistants working with persons with ASDs receive adequate education and training. All staff in schools catering for children and young persons with ASDs should receive awareness training.

Staff training and development attracted one of the highest levels of comment in the submissions, with fifty-two contributors raising the issue. The general thrust of this material was a significant concern with the lack of comprehensive, ASD-specific training for teachers, classroom assistants and others.

The comments included concerns with the current absence of systematic training and preparation, proposals as to who needs training, and how and where that training should be delivered. Many contributors simply adverted to the need for training, while others developed their points with reference to their own child, or with recommendations for change.

This Chapter examines existing provision of education and training for teachers, other professionals and support staff involved in the education and development of persons with ASDs. It will then outline a number of possible approaches in this area and will offer recommendations.

12.2 Existing Provision in the Teaching Profession

In 1993, the Report of the Special Education Review Committee (pp. 72-74) made twelve recommendations indicating the importance of specialist teacher training and in-service education for all teachers in all environments. They identified the post-primary sector as the area with the most notable gap in terms of appropriately trained teachers to serve the needs of students with disabilities and/or special educational needs¹. Again in 1996, the report of the Commission on the Status of People with Disabilities emphasised the importance of teacher education relating to pupils with disabilities and special educational needs. However, in these reports no specific reference was made to the education of teachers or other professionals in relation to ASDs. Since the publication of these important reports there have been few significant developments in the education and training of teachers and other professionals for special educational needs.

12.2.1 Education and Training Issues for Early Education

It is now widely accepted, based on international research in many countries, that early education plays a vital role in the development of children who are disadvantaged or who have disabilities and special educational needs. Indeed, this acceptance has now been adopted into Irish government policy in the White Paper on early childhood education, *Ready to Learn* (Department of Education and Science 1999). The vital role played by early education underlies the fundamental approach to the education of children with ASDs in the work of this Task Force, and the importance of such early intervention is set out in Chapter 7.

Early education provision specifically designated for children with autistic spectrum disorders, under the aegis of the Department of Education and Science is currently very limited. Although many children with ASDs, particularly some with AS/HFA, will be appropriately placed in existing home-based provision, or in mainstream community, private or Montessori provision with additional support, others will be more appropriately placed in specialist models of provision.

¹ As early as 1978 in the UK teacher education and training were identified as a top priority by the Warnock Report, and considered essential to ensure improvements in special educational provision (Warnock, 1978)

At present the Department of Education and Science provision of pre-school education for children with ASDs consists of three special classes in the Dublin area, and a pilot project in Cork. There are three teachers and six special needs assistants in the three Dublin classes. In the Cork project there are eighteen personnel, including a Director and Supervisor. There is, in addition, early education provision by the State for children with learning disabilities (which would include some children with autistic spectrum disorders) under the aegis of the Department of Health and Children. Some children with ASDs may be in receipt of early education by private providers.

The *White Paper on Early Childhood Education, Ready to Learn*, points out that the *ad hoc* development of the existing systems of qualifications means that some persons employed in early childhood education may not have acquired formal qualifications. The *White Paper* goes on to recommend that an ongoing process of training will be required to facilitate updating of qualifications and skills to take account of developments in best practice (pp. 58-59).

Training in best practice in the education of children with autistic spectrum disorders would be of extreme importance in the case of personnel working with children with ASDs. The Task Force recommends that personnel working in early education with children with ASDs be trained in appropriate interventions for children of this age, whether in pre-school provision provided under the aegis of the Department of Education and Science, of the Department of Health and Children, in private Montessori or other pre-schools, or in community playgroups.

Teacher education courses specifically targeted at the early years are, at present, provided on a limited basis in Ireland. Such courses are provided as options on the B.Ed. programmes in the primary colleges of education. There are also a number of degree programmes in the area of early childhood education, although these are not recognised professional teaching qualifications. Examples of such programmes are: the B.A. (Early Childhood Studies) at University College Cork; the B.A. in Early Childhood Care and Education at the Dublin Institute of Technology; and the Graduate Diploma in Humanities in Montessori Education at St Nicholas' Montessori College, Dun Laoghaire. All of these courses offer modules on special educational needs, although not necessarily on ASDs.

Training courses in ASD appropriate methods for early childhood education should be part of the portfolio of ASD training courses provided by the Department of Education and Science. Such programmes could also be provided by the universities and colleges of education. Indeed, the possibility of university departments of psychology and education, or teacher education colleges, having linkages to pre-school providers for children with ASDs should be explored. Arrangements of this kind are common in the United States and offer the possibility of students in such departments working with pre-school staff and

children in the use of some of the most effective methods of intervention, such as ABA and TEACCH.

It is important to highlight that specialist approaches require specific training from those qualified to provide such training. For example, the TEACCH programme has a sequential training programme, taking place over an extended time period, which involves an initial one week introduction to the approach, and then periodic, on-going on-site follow up from certified TEACCH trainers. In order to effectively implement an ABA programme instructors must undergo formal instruction and on-going, on-site supervision of their work by qualified behaviour analysts. The Hanen communication programme is another example where formal training is required. The Department of Education and Science will need to sponsor staff at two levels to insure proper training in specialist approaches:

- the training, by qualified personnel, of teachers, classroom assistants and other relevant support staff to conduct specialist programmes;
- the “training of trainers” – i.e. teachers, psychologists and other staff to secure specialist qualifications in designated areas so that they might conduct the staff training and on-going supervision needed with hands-on staff.

It is important that expertise in the empirically validated approaches be available within the schools in each geographical region. Such expertise could be provided through the appointment of appropriately qualified personnel, or by formal collaboration with staff from the universities and colleges in the regions who may be able to offer or build up such expertise.

The Visiting Teacher service could play a valuable support role to pre-school staff also (see Chapter 5 for the role of the Visiting Teacher service in schools). Obviously, the effectiveness of an ASD Visiting Teacher service would hinge upon the Visiting Teachers themselves being knowledgeable about ASDs and skilled in the appropriate interventions. This, in turn, implies that Visiting Teachers be educated about ASDs, and that they are skilled in the use of a range of interventions before taking up an appointment.

12.3 PRE-SERVICE AND IN-CAREER EDUCATION OF TEACHERS AT PRIMARY AND SECOND LEVEL

12.3.1 Special Education Provision in Teacher Education Programmes

Special education modules are now provided in teacher education programmes in all of the universities and colleges of education. They vary, however, in length and intensity and they address a wide range of disabilities and special educational needs which may, or may not, include autistic spectrum disorders. Special education inputs in B.Ed. programmes for primary teachers range from 30-42

hours over the three or four years of the undergraduate courses (Sayles, 2001). Postgraduate teacher education programmes for second level teachers provide lectures in special education varying in duration from 2-20 hours. Special education is also frequently discussed as an aspect of other subjects such as sociology and psychology (ibid.).

In-career education in special and/or remedial education for teachers is also provided in almost all of the universities and colleges. Most of such courses are provided on a part-time basis and range from one-day and one-week courses to accredited courses extending over an academic year. In-career courses for remedial/learning support teachers are provided at six centres throughout the country. These are fully supported by the department of Education and Science and recognised as a qualification for remedial and resource teaching posts at primary and second level. In the period 1995-2000 a total of 940 teachers availed of these courses. Of these, 549 were primary school teachers, 350 were post-primary teachers and 41 were tutors in Youthreach programmes, in community training centres and in the prison service (ibid.).

Two one-year, full-time, recognised courses are provided for teachers who work in special education, in learning support or in resource posts. These are in St Patrick's College, Drumcondra and in University College Dublin. Both take up to 25 students per annum. University College Dublin also provides a two-year Masters in Education in Special Educational Needs, structured to suit the needs of teachers in post.

Teachers undertaking some of the above in-career programmes receive funding and support from the Department of Education and Science, while other must undertake such essential education for the teaching of pupils with special needs entirely at their own expense, including course fees, substitution payment and subsistence away from home. The Task Force recommends that all teachers undertaking in-career recognised courses in special education, including education on ASDs, should have financial support from the Department of Education and Science.

12.3.2 Numbers of Specialist Personnel in Schools

At primary level, throughout the country, it is not possible to distinguish between specialist teachers and support staff working directly with children with autistic spectrum disorders as the Department of Education and Science databases are not kept in this way. Within the primary sector, overall, there are 701 full-time and 256 part-time resource teachers. There are a further 1,480 learning support teachers at primary level. There are currently in excess of 2,000 special needs assistants in primary schools (information provided by the Department of Education and Science).

At second level, throughout the country, there are 335 resource teacher posts and a further 290 learning support posts. The number of special needs assistants in second level schools is 140 at present (information provided by the Department of Education and Science). Earlier in this Report we have recommended the establishment of an ASD Visiting Teacher service, whether the children with ASDs are receiving home-based education, pre-school, mainstream primary or second level education, and specialist education. This will be a support and advisory service, available to both teachers and families. All of these teachers and support personnel, and those to be appointed in the future, will require autistic disorder/AS/HFA education and training.

12.3.3 Education and Training: Issues and Problems

In 2000 there were 242 special needs resource teachers serving primary schools (Irish Association of Teachers in Special Education (IATSE) 2000) and, as indicated in the figures above, in the last year a further 1,050 (either full- or part-time) have been appointed. A survey conducted among resource teachers in Spring 2000 (Ibid.) showed that just fifteen per cent of the respondents at that time had certified special education training prior to appointment. Just eleven per cent of the respondents had induction training after their appointments. The lack of training for resource teachers has been a problem for some considerable time. In a research study of resource teachers at second level in the early 1990s (Lynch and McCurtain 1994) for example, it was found that a majority stated that they were “less than adequately” prepared for their work.

The paucity of training for special needs resource teachers (for any kind of special educational need), together with the almost complete absence of training for teachers of pupils with autistic spectrum disorders (until a very recent initiative taken by the Department of Education and Science to establish distance education for twenty-five teachers of pupils with ASDs with Birmingham University – see below), indicates a crisis in the education of pupils with ASDs and other disabilities, which must be addressed:

A large investment is being made in supplying Resource Teachers to support integration of children with special needs in mainstream education. But placing unsupported teachers into schools and hoping they learn to function successfully is not good enough. A major step towards providing what parents and Government want has been made, but the Resource Teacher Service is, at present, like a power tool without an energy source. Support, training and funding are needed to provide it with the energy to fulfil its potential (IATSE 2000, p.5).

Reference has already been made to the pervasive and multi-faceted nature of the condition of autistic spectrum disorder, the range of seriously disabling conditions which frequently accompany it, and the range and severity of the challenges experienced by the teachers of pupils with ASD. In addition, the education of pupils with ASDs involves the assessment and teaching of social, developmental, communicative and life skills, which do not normally form part of the responsibilities of classroom teachers.

In a recent comparative study of teachers of pupils with ASDs in the Republic of Ireland and Northern Ireland (Kinsella 2000), the teachers reported the allocation of significant proportions of their weekly timetables to the teaching of each of four developmental skill areas: communication; social development; play; and self-care. These teachers therefore would have required high levels of specialist expertise in addition to their basic training, together with regular and ongoing training in the various new approaches which are being developed in the education of children with ASDs. The vast majority of these teachers held the basic primary teaching qualification required in their jurisdictions, and a number of teachers, especially those from the Republic of Ireland sample, had obtained additional qualifications at degree or postgraduate levels. Approximately half the total sample had acquired additional postgraduate qualifications in Special Needs Education. However, only half of the total sample of respondents reported that training in Special Needs Education formed a component of their basic teacher training, and less than half of the respondents had the option of a teaching placement in the area of special needs education as part of their basic training (ibid.).

In this comparative study of teachers North and South (ibid.) there was a marked contrast between the teacher samples from the two jurisdictions, in terms of their reported satisfaction ratings with the adequacy of their pre-service and in-career education, as preparation for the teaching of children with ASDs. A greater proportion of teachers from Northern Ireland expressed satisfaction with their education in this regard than did teachers from the Republic of Ireland. A number of teachers from the Republic of Ireland sample commented on the lack of such support and expressed the view that even the kind of intensive, external, one-day or five-day courses mentioned above do not enable teachers to effectively implement existing and emerging approaches to the education of pupils with ASDs. These teachers expressed the view that ongoing, school-based guidance in the implementation of such approaches would be beneficial, and that the services of an advisory teacher would greatly facilitate this process.

Half of the teachers from the Republic of Ireland sample indicated that in-career opportunities were never available to them or else were only available every four years or more. With regard to forms of in-career development which are specifically related to the teaching of pupils with ASDs, almost all teachers in the total sample had received training in the application of the TEACCH approach. This training had usually consisted of five-day courses. In addition, a minority of

teachers within the Republic of Ireland sample, mostly within the Beechpark Services Schools, had received training in new approaches to communication from the Speech and Language therapist. Just over half of the Republic of Ireland sample reported having received training in the formulation of IEPs, while two-thirds had been trained in formulating Behaviour Support Plans. Less than one-third of the teachers from the Republic of Ireland sample reported that they have the opportunity to attend seminars on ASDs a minimum of once each year (ibid.).

All teachers included in this comparative study prioritised the management of challenging behaviour as an area in which further professional support in the form of in-career training is required. Other areas of priority included strategies to cope with the communicative impairments, and training in assessment procedures and strategies for the development of the social skills, self-care skills and play skills of pupils with ASDs. Many teachers cited the lack of adequate resources and of effective in-service training as adding considerably to the challenges of teaching pupils with ASDs.

In the last two years, however, with the growing awareness of the needs of children with ASDs, and of the need of teachers for specialist training in ASD appropriate techniques, the Department of Education and Science has embarked on intensive training programmes in the area of ASDs. These include a series of one, three and five-day training courses in a number of centres in different parts of the country. They also include a professional training programme for twenty-five teachers run by the University of Birmingham and St Patrick's College, Drumcondra, which commenced in January 2001. Another twenty-five teachers will commence in January 2002. The Department's stated longer-term objective is to add to the level of expertise that already exists in Ireland in the special needs area, thereby enabling the design and delivery of training courses by Irish experts to meet the ongoing training requirements as they arise. Courses provided by the In-Career Development Unit of the Department of Education and Science are itemised in Appendix 15.

12.4 TOWARDS GOOD POLICY AND PRACTICE

In-career professional development in the area of special needs education in general, and in the teaching of pupils with autistic spectrum disorders in particular, are issues of major importance if an effective system of special needs education is to be established for pupils with ASDs. Such issues assume even greater significance within the Republic of Ireland, where the current expansion in educational provision for pupils with ASDs frequently necessitates the appointment of teachers with no prior experience in the teaching of pupils with ASDs, and possibly no training or experience within any area of special needs education.

The study cited above indicated the need for a forum in which to liaise with other teachers of pupils with ASDs. It is noteworthy that the *Report of the Planning Group (Department of Education and Science 2000)* recommends that the National Council for Special Education establish a consultative forum in order to facilitate the participation of interest groups in policy formation and the Minister has recently announced the establishment of the Council. The Task Force welcomes the establishment of this Council and recommends that it establish a consultative forum.

From the point of view of children with ASDs, appropriate pedagogies are of critical importance. These must be empirically defensible and based upon the findings on best practice in international research. They must also be subject to ongoing critical evaluation and review. It is important to assess, on an on-going basis, which form of pedagogy, and in which mix with other pedagogies, is most appropriate to the needs of the child with an ASD at various stages of his/her development. Teachers of students with autistic spectrum disorders should be skilled in a range of different interventions and should have a good understanding of the nature of autistic spectrum disorders. They should also be trained in appropriate behaviour management analysis and strategies.

The issue of curricular differentiation is also an important one for mainstream teachers who may have a child with an ASD in their mainstream class. Such teachers would need support in planning curriculum adjustments to suit the needs of the ASD child. The role of the visiting teacher would be of particular importance here, as well as in-career courses to address this issue.

An ASD-appropriate in-career development programme for teachers should include a hierarchically sequenced menu, to guide teachers so that they receive the minimum basic information and skills first, and then move on to progressively important topics of training. The minimum knowledge base prior to assignment to a special class or child should be designated, and a timetable for working through the menu established. Elsewhere in the Report, the Task Force recommends the appointment of Special Needs Officers operating in regional centres. Where appropriate, the hierarchically sequenced menu recommended above could be developed in conjunction with the Special Needs Officers in the relevant regional centre. There is also a role for Education Centres in running in-service courses in ASD-appropriate methods for teachers, in conjunction with the proposed Special Needs Officers or with other relevant agencies.

A greater level of support for in-career development for teachers is essential. It could be very valuable to teachers if there were paid inservice days the week (or the two weeks for new teachers) prior to the formal start of each school year. The provision of suitably experienced substitute teachers during school days to release teacher for inservice training would also provide further welcome support. The quality of education provision for children with autism depends to a large extent on the competence and confidence of their teachers. A recent study of teachers of

children with ASDs in Ireland suggests that appropriate induction programmes, while initially benefiting the teachers, will ultimately be of great significance to pupils with ASDs (Balfe 2001). It was evident from this study that a high percentage of the teachers being employed had little or no knowledge of ASDs, therefore it would seem to be advisable that teachers appointed to classes for children with ASDs be given access to a certain body of knowledge prior to beginning to teach or as soon as possible afterwards.

As research indicates that almost one in three hundred children have AS/HFA (Ehlers and Gillberg, 1993), and are most likely to be placed in mainstream classes, AS/HFA is likely to be one of the disabilities most commonly encountered by mainstream teachers. If the prevalence figure cited above is applied to the current pupil populations of the primary and second level sectors (Department of Education and Science, 1999) the figure for primary schools would be in the region of 1,680 and for second level schools approximately 1,342 pupils with AS/HFA. Therefore, it is important that teachers are aware of the nature of this disorder. The needs and difficulties of intellectually able children who have severe social and communication impairments present a challenge which can only be addressed by ensuring that modules on AS/HFA are included in pre-, and in-service, teacher education for primary and second level teachers.

As there are relatively few well-controlled research studies on isolating and empirically evaluating optimal educational interventions for pupils with AS/HFA, there is a significant need for research in this area. However, general educational strategies for pupils with AS/HFA (see Appendix 10 for general guidelines) have recently become more plentiful in professional publications (Fullerton, Stratton, Coyne, and Gray 1996; Klin & Volkmar, 2000; Kunce and Mesibov, 1998).

Teaching practices and approaches, behavioural management techniques, strategies for emotional support, and activities intended to foster social and communication competence-should be conceived and implemented in a thoughtful consistent (across settings, staff members, and situations) and individualised manner...It should be noted, however, that there are different degrees of concreteness and rigidity, paucity of insight, social awkwardness, communicative one-sidedness, and so forth, characterising individuals with AS (and HFA) and that the particular circumstances and patterns of strengths and weakness all require consideration.(Klin and Volkmar, 2000).

The training of teachers of pupils with AS/HFA in mainstream classes will need to address the characteristics and core impairments of AS/HFA and the vulnerability and possible social isolation of these pupils. It should ideally focus on the identification of strategies for enhancing communication, social competence, independence, and academic performance (see Chapter 8 for recommended mainstream intervention and bibliography section for

reading/material resources). The key elements of best practice that should be incorporated into the training of teachers of mainstream primary and second level schools of pupils with AS/HFA includes:

- regular home/school liaison and meaningful collaboration between parents, teachers and relevant health professionals;
- development of pupil's focus of interest;
- the use of well planned IEPs that include plans for unstructured time;
- development of structure, the organisation of time and preparation for changes (however small) to the classroom routine;
- social/communication skills training;
- integration within the school, and the identification of strategies to promote social acceptance among peers;
- understanding of the uneven cognitive profiles of pupil's with AS/HFA;
- effective strategies for the prevention of bullying.

In addition, information packs and guidelines on both AS/HFA and autistic disorders should be drafted by the Department of Education and Science, in conjunction with NEPS, and circulated to all schools. Initial teacher training and continuing professional development courses should include modules on AS/HFA, including strategies for coping with bullying as submissions to the Task Force suggest that this is a serious problem for young persons with AS/HFA in particular (see also Chapter 5).

There is clearly a need for university education departments and colleges of education to provide modules on special education as a mandatory element of their courses and to include ASD education as part of such modules. In fact, as indicated earlier, most pre-service courses already incorporate modules on special education as separate elements or as part of their psychology of education programmes. The greatest difficulties in incorporating an adequate training in ASD-related issues are presented in post-graduate teacher education courses, such as the Higher Diploma in education, since these programmes are already very intensive and the curricula somewhat over-crowded. Therefore, creative approaches to pre-service training will need to be utilised, e.g. videos of good practice, relevant commercial videos and CD-ROMs, use of the Internet and so on.

Submissions to the Task Force also reflected on the content of training for specialist teachers. The terms “specialized” and “autism-specific” came up frequently in the material on professional development. With regard to the content of teacher training and education, the main theme was that teachers should be equipped with the knowledge of all currently recognised methodologies, so that they can select the approach or mix of approaches most suited to the needs of the student at any given time. Other content areas for training mentioned included training in the preparation of Individual Education Programmes, training in development of ASD-sensitive curriculum, training on the core triad of the difficulties involved in autistic spectrum disorder, and the development of skills with which to address low self-esteem.

Teacher education programmes for students with ASDs should also focus on meaningful collaboration with other professionals in the field of ASD, including inputs on working with the parents and families of pupils with AS/HFA. An emphasis should also be placed upon working with and including parents, special needs assistants and visiting teachers, as well as on the principles of guidance and counselling. Team teaching methods and team-work skills should also be incorporated into any specialist needs training for educators of pupils with ASDs. Knowledge of the work of specialist staff, such as psychologists and speech therapists, should be made available. Opportunities for joint training of teachers and other specialist support staff and clinicians in ASD-appropriate methods should also be explored by the Departments of Education and Science and Health and Children, and also by the universities.

People with an ASD, especially those who have partaken in third level education, could very valuably be invited to make contributions on teacher education courses. This would enhance the understanding of teachers in meeting the challenges of teaching pupils with ASDs.

Induction programmes should also be organised for any teacher, visiting teacher or special needs assistant who is taking up for the first time a post with defined responsibility for the teaching or care of children with autistic spectrum disorders, whatever the stage of his/her career. Recent research in Ireland (cited above) shows that very few special needs resource teachers have had any such induction.

12.4.1 Teacher Education and ASD Awareness: a Whole-School Approach

To meet the needs of pupils with autistic spectrum disorders, and of other pupils with disabilities and special educational needs, the improvements outlined above in the present provision of teacher education are imperative. Schools should also have in position a ‘whole school policy’ on special needs and disabilities, including ASDs. A whole school policy would imply that all staff - principal, post-holders, teachers, ancillary staff, parents and, in some cases, students - would be involved in the development and implementation of policy. This is of very

particular importance in schools where pupils with autistic spectrum disorders are in attendance. At second level, special needs post-holders, guidance counsellors, year heads and tutors will have an extremely important role to play in the support of pupils with ASDs, especially pupils with AS/HFA as these are the most likely pupils to be mainstreamed. While disability and ASD awareness training are important for all staff, additional in-career training opportunities are essential for special needs post-holders, guidance counsellors, year heads and tutors.

These issues were also strongly reflected in the submissions. As well as training for special classes and special school teachers, resource and remedial teachers, many of the submissions to the Task Force called for training and awareness-raising for school principals, boards of management and mainstream classroom teachers. The access of teachers in rural areas to opportunities for training was also mentioned.

A range of delivery mechanisms for teacher education and in-career development in relation to ASDs are possible. These include:

- Modules on ASD in pre-service programmes;
- Ongoing in-career development;
- Post-graduate training for qualified teachers, providing in-depth knowledge of ASDs and methodologies;
- Opportunities for skills updating;
- Conferences, exchange visits, special interest groups, cross-border initiatives;
- Provision of material on the internet;
- Use of inputs from experts in relevant fields.

12.4.2 Standards in Teacher Education and Training

It should be noted that under the provisions of the *Teaching Council Act* it is envisaged that the Council will review and accredit programmes of teacher education and training provided by institutions of higher education and training in the State. It will also have the function of reviewing the standards of education and training appropriate to a person entering a programme of teacher education and training. It will, thirdly, review the standards of knowledge, skill and competence required for the practice of teaching. The Council shall also promote the continuing education and training and professional development of teachers.

The Task Force recommends that all ASD education and training courses be periodically evaluated and that, in its review and promotional functions, the Teaching Council should have particular regard to the education and training of teachers in relation to ASDs.

12.4.3 Research

No future development of in-service training for those professionally committed to the teaching of children with special educational needs would be complete without the provision of opportunities for training and research at a high level. More advanced courses leading to qualifications in aspects of specialist education are required in Ireland and opportunities should be provided to teachers, head teachers and other professionals to take higher degrees in the field of their choice. In view of the limited research in Ireland on the education of people with autistic spectrum disorders there is a very pressing need for high quality evaluation studies and basic research into the education and interventions most appropriate for people with ASDs.

One way to advance the development of appropriate research and development would be for the Research and Development Committee of the Department of Education and Science to prioritise, and provide significant funding for, university research on classroom practice and the outcomes of different intervention strategies with children with ASDs at all levels of the education system. In this way, the relationship between teacher education and research would be strengthened and many issues raised by this Task Force could be addressed.

12.4.4 Education and Training of Other Professionals and Support Staff

Although the main focus was on teacher education and training, the submissions to the Task Force also identified a need for asd specific training for all other professionals working with children with ASDs, and their families. In the submissions, the concerns and proposals about teacher training and education were applied in almost equal measure to training for classroom assistants and special needs assistants. This training should be given before the assistants commence work. There should also be access to funding for further education and development for in-post holders. Accredited training courses should be established for classroom assistants as part of an accreditation ladder providing possibilities of career progression.

As well as therapists and members of multi-disciplinary teams, training is seen as necessary for parents, General Practitioners, nurses, Gardai, bus drivers, taxi-drivers, escorts, carers, pre-school and nursery staff, care staff, house-parents, and educational authorities. This broad approach was typified by the following comment in the submissions to the Task Force:

All professionals likely to come in contact with autistic children should be required to have basic acquaintance with the condition and its implications.

It is of particular importance that school inspectors are given the opportunity of updating their knowledge and awareness of issues relating to ASDs and related

educational provision as part of their programme of professional development. The joint attendance of inspectors and psychologists at inservice courses is appropriate in some instances.

Training for occupational therapists in sensory integration is proposed in the submissions and is supported by the Task Force. All therapists should also receive training which would give them a grasp of the application of teaching methodologies.

The central importance of training for parents was emphasised in several submissions. It was proposed that specialised training should be given to educators, parents and siblings to maximise communicative environments for children, and to reinforce programmes being delivered by the schools, and that this training should be delivered by personnel with expertise in autistic spectrum disorders. A further point made concerns the need for joint training for those working together as part of multi-disciplinary teams. Teachers, parents, classroom assistants, and the clinical team should engage in joint training.

With regard to Health Board personnel, the following suggestions were made in the submissions:

All staff require experience in working with a range of client groups prior to working specifically with children with ASDs and their families.

As staff will be working both in health and education settings, a working knowledge of the organisational issues is essential.

Occupational therapists require training in sensory integration.

Experience will aid in working with families whose children are receiving services from both statutory bodies.

Training for after school home-help was recommended as a means of extending the child's programme, with a focus on life skills.

12.4.5 Psychologists

12.4.5.1 Health Board Psychologists

The Task Force has recommended that educational provision, support and placement be based upon multi-disciplinary assessment and a statutory statement of need (see Chapters 4 and 13). It is envisaged that, for the foreseeable future, the psychologists involved with the process of initial assessment and Statementing will be Health Board psychologists, as the National Educational Psychological

Service has a separate, clearly defined role in relation to support services within schools. In addition, neither the present, nor proposed numbers within the NEPS would provide the capacity for a Statementing service. The Task Force therefore recommends that training for Health Board psychologists include ASD-specific training, and that in-career development relating to ASDs be provided for serving Health Board psychologists.

12.4.5.2 Educational Psychologists

Although education was one of the earliest proving grounds for the emerging science of psychology in the late nineteenth and early twentieth centuries, and professional psychological services to schools emerged in the USA and Britain soon thereafter, the Irish Republic was to wait until 1959 for the City of Dublin Vocational Education Committee to establish the first School Psychological Service here, with the Department of Education Service emerging in 1965 and employing three psychologists; by 1997/98 it had grown to 20 psychologists serving 346,000 pupils, working mainly in post primary schools. The National Educational Psychological Service (NEPS) Development Plan envisages the employment of 200 psychologists at primary and post primary levels by the end of 2003. Meanwhile the CDVEC service has grown to employ five, while the County Dublin VEC has developed its own service in which three are currently employed. In addition, a number of educational psychologists are employed by the Health Boards and psychologists employed by Voluntary Bodies work in a number of Special Schools.

The need for a comprehensive educational psychology service in the Irish educational system has been highlighted for a number of years. For example, in 1993 the *Report of the Special Education Review Committee*, pointed out that there was virtually no primary School Psychological Service provided under the aegis of the Department of Education at that time and that the service to post-primary schools was necessarily limited. This important report accordingly recommended:

An expanded School Psychological Service, staffed by psychologists with appropriate qualifications, under the aegis of the Department of Education and/or the proposed intermediate educational administrative structures, should be established on a countrywide basis without delay (p.32).

The Department of Education and Science itself has documented the fact that there is no educational psychology service available in the majority of primary schools. At post-primary level, provision is very limited because of the current very high ratio of educational psychologist to school population. In some instances psychologist to child ratios of up to 1:18,500 still prevail.

As mentioned above, the Development Plan of the National Educational Psychological Service envisages the eventual appointment of 200 psychologists by the end of 2003. A Press Release (Department of Education and Science, 2 August 2001) stated that this objective will now be met by the end of 2002. The Minister for Education and Science also recently announced a new initiative whereby funding is being made available to schools not yet covered by NEPS to purchase assessment services from suitably qualified private psychologists. This initiative is designed to “alleviate the bottlenecks” pending the full establishment of NEPS.

As pointed out in Chapter 4.11, the current target of 200 psychologists will not be sufficient to undertake the intensive individual work required for pupils with ASDs. When NEPS is at full established strength an effective ratio of 1:5000 will prevail. This ratio compares very unfavourably with those of our British counterparts. In Northern Ireland, for example the ratios range from 1:3,083 to 1:3,555 in four of the Education and Library Boards (DENI, 2001).

The U.K. ratios, however, are predicated on the basis of enabling the educational psychologists to address the needs of children with significant disabilities such as ASD, whereas the computation of the target number of 200 psychologists to be employed in this country did not factor in the intensive individual work involved with such children. The planning for NEPS preceded the Government’s decision of October 1998 to recognise the entitlement of all students with disabilities within the mainstream national schools system to automatic provision to meet their needs, and the subsequent issuing of Circulars by the Department of Education and Science in relation to the accessing of such provision.

At this stage it is clear that neither the current nor projected staffing levels in NEPS can enable the psychologists to undertake interventions of the level which is required with children with ASDs. NEPS, however, is about to undertake a mid-term review of staffing needs, and it is to be hoped that an increase in staffing levels will eventuate, which will enable the educational psychologists to have an increasingly important role in relation to children with ASDs, as well as children with a variety of other special educational needs.

Many of the educational psychologists currently working with the health and education services have been trained as clinical psychologists. As stated above, it is envisaged that clinical and other Health Board psychologists will continue to play an important role in the support of children with ASDs, especially with regard to Statementing.

There are, at present, just two avenues for qualification as an educational psychologist in the Republic of Ireland: one is the Masters Degree in Educational Psychology at University College Dublin; the other is the Postgraduate Diploma in Professional Psychology (Educational Psychology) offered by the Psychological Association of Ireland. The UCD course, established in 1994 has

been, up to the present, restricted to six graduates per year and has produced a total of 32 since its foundation. The PSI Postgraduate Diploma has, to date, graduated a much smaller number of candidates. In the light of the very pressing need for professionally qualified educational psychologists in the NEPS and in the other education and support services, there is a need for expansion in the numbers of appropriately qualified and accredited graduates. Such training programmes are extremely intensive and necessarily require significant resources to meet with the requirements of professional accreditation and regulation. The Task Force, therefore, recommends that targeted funding be provided by the Department of Education and Science, via the Higher Education Authority, to support professional programmes in educational psychology, and that such programmes include ASD-specific training, in order to meet the needs of children and families with ASDs and other special educational needs.

It is also important that educational psychologists should have access to relevant inservice support in the area of autistic spectrum disorders, preferably on a collaborative basis with clinical psychologists.

12.4.5.3 Speech and Language Therapists and Occupational Therapists

There are two forms of therapy which are of particular importance in the development and support of children with ASDs. These are speech and language therapy and occupational therapy. The severe shortage of speech and language therapists nation-wide also emerged strongly from the submissions. In the Republic only Trinity College Dublin offers courses in Clinical Speech and Language and Occupational Therapy. In 1999, the number of first year students on these courses was twenty-five in Clinical Speech and Language and twenty-nine in Occupational Therapy. In 2000, the respective numbers were twenty-six and thirty-five respectively. In the case of Clinical Speech and Language Therapy, there was an increase in the number of places offered, from twenty-six to twenty-nine for 2000/2001. However, one student did not register, and a further two have left. Leaving twenty-six (Information obtained from the Higher Education Authority). Given the crisis in supply of these therapists, it is unlikely that this annual intake will go anywhere near meeting the needs of children with ASDs and other disabilities. ASD-appropriate methods should form an essential part of the education and training of these therapists. In career training in ASD-appropriate methods should form part of the in-career development of all speech and language therapists working with persons with ASDs. Training for occupational therapists in sensory integration is proposed, as well as training which would give therapists a grasp of the application of teaching methodologies.

The Task Force therefore recommends an increase in targeted funding, via the Higher Education Authority, for the education of increased numbers of speech and language therapists and of occupational therapists.

12.5 Recommendations

The following recommendations are therefore made in relation to the pre-service and in-career development of teachers of pupils with ASDs and of other professionals and support staff.

The Task Force recommends:

1. that personnel working in early education with children with ASDs be trained in appropriate interventions for children of this age, whether in pre-school provision provided under the aegis of the Department of Education and Science, of the Department of Health and Children, in private Montessori or other pre-schools, or in community playgroups;
2. that the Department of Education and Science assume full responsibility for the provision of funded in-career development of teachers of pupils with ASDs to ensure that all such teachers are proficient in the teaching of the requisite developmental skills and in the formulation and evaluation of Individualised Education Programmes (IEPs); that training be provided in the implementation of specific approaches to the teaching of pupils with ASDs such as Applied Behaviour Analysis (ABA), TEACCH, the Hanen Communication System, the Picture Exchange Communication System (PECS) and other emerging strategies; that differentiated training for teachers working with Asperger's Syndrome be provided; that the proposed Visiting Teachers be educated about ASDs, and that they are skilled in the use of a range of ASD specific interventions before taking up an appointment; that all teachers undertaking in-career recognised courses in special education, including education on ASDs, have financial support from the Department of Education and Science;
3. that the proposed Special Needs Organisers in regional centres assume a central responsibility for organising in-career training of teachers of pupils with ASDs at regional level; that a hierarchically sequenced menu be provided, to guide teachers so that they receive the minimum basic information and skills first, and then move on to progressively important topics of training; that the minimum knowledge base prior to assignment to a special class or child be designated, and a timetable for working through the menu be established;
4. that the Department of Education and Science ensure that adequate educational resources are provided both to teachers and to schools to meet the special educational needs of pupils with ASDs and to facilitate the implementation of specific approaches to the teaching of such pupils.
5. that induction courses which incorporate training in specific approaches to the teaching of pupils with ASDs be made available to all teachers assuming a post as

- a teacher of pupils with ASDs for the first time; that the proposed the Special Needs Organisers play a role in organising these courses at regional level;
6. that the Department of Education and Science, in conjunction with the National Educational Psychological Services (NEPS), formulate guidelines for teachers of pupils with ASDs on appropriate responses to challenging behaviours; that these guidelines be implemented uniformly in all schools enrolling pupils with ASDs.
 7. that the Department of Education and Science encourage teachers and other personnel engaged in the education of pupils with ASDs in the furtherance of their knowledge and expertise by providing funding for further study and research in this area;
 8. that research be conducted on the optimal educational interventions for pupils with AS/HFA; that the Research and Development Committee of the Department of Education and Science prioritise, and provide significant funding for, research on classroom practice and the outcomes of different intervention strategies with children with ASDs at all levels of the education system;
 9. that all ASD education and training courses be periodically evaluated and that, in its review and promotion functions, the Teaching Council have particular regard to the education and training of teachers in relation to ASDs;
 10. that training in Special Needs Education be an integral part of the basic training of all teachers; that modules on AS/HFA be included in pre- and in-service teacher training for primary and second level teachers;
 11. that expertise in the empirically validated approaches be available within the schools in each geographical region;
 12. that teachers of pupils with ASDs, including teachers in special pre-school classes, have the opportunity to attend funded in-service courses in the education of children with ASDs on at least an annual basis;
 13. that teachers of pupils with ASDs be specifically and adequately trained in the management of challenging behaviours on the part of pupils with ASDs, with particular emphasis on the use of non-aversive techniques in responding to such behaviours;
 14. that training for Health Board psychologists include ASD-specific training, and that in-career training be provided for serving Health Board psychologists;
 15. that the Universities be funded to develop or expand their clinical training programmes to include ASD training, at the undergraduate and post-graduate

- levels; that all clinicians be versed in the various major approaches to educating persons with an ASD;
16. that funding by the Department of Education and Science, via the Higher Education Authority, be targeted to support professional programmes in educational psychology, and that such programmes include ASD-specific training, in order to meet the needs of children and families with ASDs and other special educational needs;
 17. that funding be increased and targeted, via the Higher Education Authority, for the education of increased numbers of speech and language therapists, occupational therapists and behaviour specialists;
 18. that a National Forum be established to facilitate communication between teachers and other personnel who are working in the field of ASDs;
 19. that all professionals and working with persons with ASDs, should receive on-going training in the distinct disorders on the autistic spectrum, in general ASD issues, and in the specific disciplines as related to ASDs;
 20. that programmes be established to qualify persons as classroom assistants in colleges and post-secondary training institutions; that there be access to funding for further education and development for classroom assistants; that accredited training courses be established for classroom assistants forming an accreditation ladder leading to career progression;
 19. that all staff working with children and families with ASDs receive ASD specific training; that specialised training be given to educators, parents, siblings and home helps to maximise communicative environments for children, and to reinforce programmes being delivered by the schools, and this training be delivered by personnel with expertise in ASDs.

CHAPTER 13

IMPLEMENTATION STRUCTURES

13.1 INTRODUCTION

This Chapter will indicate the possible structures that should be created to secure educational provision and support services for individuals with an ASD in Ireland. It will outline structural provision for:

- Inter-Departmental Co-operation
- Regional ASD Educational Planning and Advisory Service
- Identification, Diagnosis and Recording
- Assessment of Educational Needs
- Statutory Statement of Educational Needs
- Appeals System
- Review of Progress
- Differentiated Range of Provision – Early and Pre-school, Primary, Second, Third Level and Continuing
- Curriculum Development
- Inspection and Evaluation;
- Advisory and Training Support Services

Finally, the Chapter will indicate the administrative and funding issues which the Task Force on Autism recommends should be addressed to meet the needs effectively of all individuals with ASDs in Ireland.

The Task Force findings make it imperative that a co-ordinated approach is implemented by statutory bodies, most importantly by the Department of Education and Science, the Department of Health and Children and the Department of Enterprise, Trade and Employment.

It is the consensus of the Task Force that the Department of Education and Science accepts the need to secure and maintain effective educational support and provision, including diagnosis and assessment and support services, for all children and young people with an ASD. Such support and provision must develop from structures that are judiciously established and inclusive, and recognised widely by individuals with ASDs, who can access provision within a given timescale.

Structures for the delivery of services to persons with autistic spectrum disorders have been proposed in a succession of reports over the years from the Departments of Education and Science and of Health and Children. Many of the recommendations identified within these reports and cited in detail in Chapter 15

on Policy, have not yet been realised convincingly across the country, and have failed to meet the needs of many persons with autistic spectrum disorders.

In a number of the submissions to the Task Force, there is a clear indication of the need for a formal structure to clarify and direct provision across the country. Much of the evidence highlights the anguish of parents when faced with limited responses from the state services to their children's needs, and the extreme variation when services are compared across the regions. In some fifteen submissions, for example, there are specific proposals for new, clearly defined structures, at regional and national level, to secure the quality of service and its delivery.

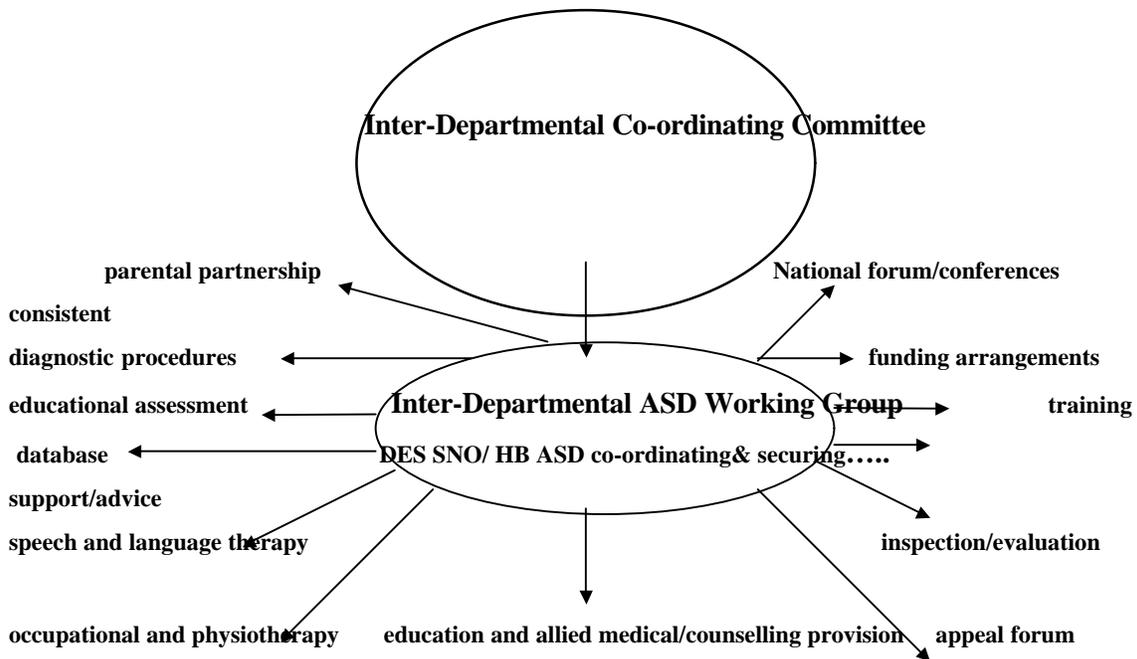
The Task Force proposes the acceptance of the structures described below and recommends that they are implemented. The proposals reflect issues identified in the submissions, the expert views of the Task Force itself, and international best practice, and support, *inter alia*, recommendations on re-structuring the Department of Education and Science contained in two reports commissioned by the Department: *Review of Department's Operations, Systems and Staffing Needs* (2000), and the *Report of the Planning Group: A National Support Service for Special Education for Students with Disabilities* (2000). The Task Force proposals also support the introduction of a National Council for Special Educational Needs announced by the Minister of Education and Science on 2nd August 2001.

13.2 RECOMMENDATIONS FOR STRUCTURES TO SERVE THE NEEDS OF CHILDREN AND YOUNG PEOPLE WITH AUTISTIC SPECTRUM DISORDERS

13.2.1 Inter-Departmental Co-operation

The Task Force's findings identify the pressing need for the Department of Education and Science to create a continuum of appropriate educational provision for children and young people with autistic spectrum disorders in formal co-operation with the Department of Health and Children, and the various health boards. The Inter-Departmental Co-ordinating Committee (recommended by the 1993 S.E.R.C. Report to co-ordinate provision between Education and Science and Health and Children, and subsequently established on foot of that recommendation), and the internal Planning Group established in the Department of Education and Science (see 15.1.7 of this Report), should reflect the Task Force recommendations for the different levels within the education and health systems, and initiate immediate action by both Departments to secure effective implementation of provision for persons with ASDs. In order to effect this, an Inter-Departmental ASD Working Group should be established as a sub-committee of the Inter-Departmental Co-ordinating Committee. Its general remit should include the production of a Service Level Agreement to indicate clearly

the responsibility, including resources, of each Department, in order to secure and to implement educational provision and support services for persons with ASDs. It should also include the setting up of a formal structure of co-operation and co-ordination in each Health Board Region between the Department of Education and Science Special Needs Organiser, and the Health Board ASD Co-ordinator.



13.2.2 Regional Autistic Spectrum Disorder Educational Planning and Advisory Service

It is, however, the Task Force's position that more permanent, educational structural arrangements should be established by the Department of Education and Science. As such, at regional level, the Task Force concludes the need for an Autism Spectrum Disorder Educational Planning and Advisory Service under the administrative and management control of the Regional Special Needs Organiser (recommended from the Expert Advisory Group Structure to be established by the National Council for Special Education which was recommended in the Department of Education and Science *Report of the Planning Group: A National Support Service for Special Education for Students with Disabilities* [2000]). This Service should be supported strategically in its work by NEPS.

Consequently, the Task Force recommends, at regional level, the creation of a Regional Autistic Spectrum Disorder Educational Planning and Advisory

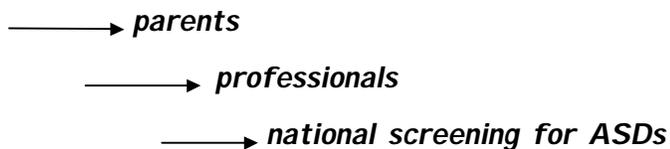
Service, under the joint authority of the Department of Education and Science and the National Council for Special Education, administered and managed by a Regional Special Needs Organiser, and supported by a multi-assessment planning team, to identify and secure effective provision for children with ASDs within a Statutory Statement of Educational Need. This Regional Autistic Spectrum Disorder Educational Planning and Advisory Service should be established within each Health Board region, and should work in formal collaboration with the Health Board ASD Intervention Services facilitated by the Health Board ASD Co-ordinator, so as to ensure the automatic delivery of the necessary support services.

13.2.3 Identification, Diagnosis and Recording

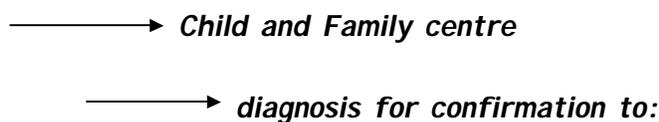
The Task Force welcomes the introduction and the development of ASD diagnostic and assessment services, within each Health Board region to prioritise the task of identification and diagnosis of autistic spectrum disorders. The references to identification and referral dealt with in this Report provide the health authorities with sufficient information and direction to promote consistency and cohesion in health board practices across the country. These references include:

- early detection arrangements;
- national screening for ASDs;
- open referral through GP services and, where available, to ASD support services.

Early Detection ('Primary' referral) by:



Referral ('secondary') for diagnostic testing within a four week period of referral



Referral ('tertiary')

—————→ **Independent Health Board ASD team**

Diagnosis within an eight weeks period from referral:

—————→ **confirmed diagnosis**

—————→ **written information shared with parents**

—————→ **recording in national ASD databank**

—————→ **Family/Child Care Support Plan**

13.2.4 Assessment of Educational Needs

The Task Force recommend, as an interim measure, and until such times as independent diagnostic services, as recommended by the Task Force, have been agreed and implemented, that the current Health Board arrangements (including whatever ASD Services are available, facilitated by the newly established post-holders for ASD co-ordination within the Health Boards) should convey the details of the ASD diagnosis, and the impact of the diagnosis on the child's or young person's ability to learn and to socialise, in order to assist the Department of Education and Science Inspector, and the multi-disciplinary team to identify appropriate interventions and supports for persons diagnosed with an ASD. This action would clearly provide vital information to parents, teachers and others planning and implementing educational intervention programmes, in particular, at pre-school and at subsequent levels. At all times the provision of the necessary support services, as set out under the Child and Family Support Plan, will be the responsibility of the Health Board ASD Intervention Service, facilitated by the Health Board ASD Co-ordinator.

13.2.5

The recommended structures for the assessment of educational needs, as set out in earlier Chapters of this Report, are summarised below. First the composition of the Team is outlined, followed by the Task(s) they must perform.

The Team

- *Special Needs Organiser (administration)*
- *educational /clinical psychologist (to be from ASD Diagnostic Team for continuity)*
- *teacher, ASD advisor, therapists as required)*
- *parent/guardian*

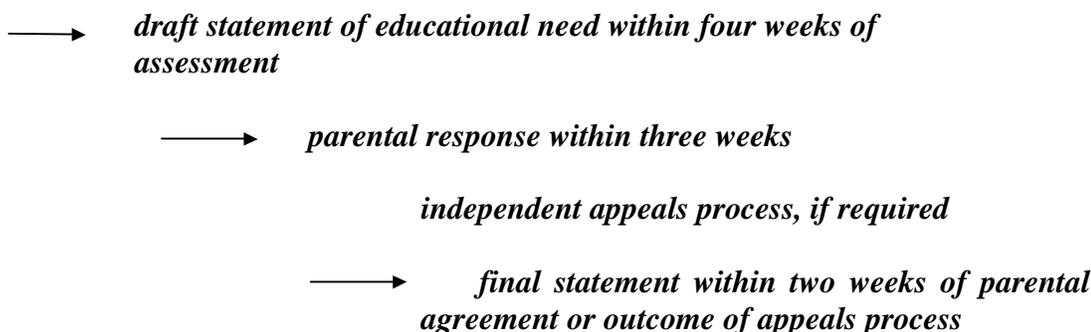
The Task

- *multi-assessment information collation*
- *identification of educational needs including resource implications*
- *draft statement of educational need*
 - ↙
 - ↘*educational targets / placement*
- *final statement of need signed by parent/guardian*
- *relevant providers informed*
- *provision date specified for implementation*
- *training needs identified*

Statutory Statement of Educational Needs

Statutory Educational Statementing Procedure

- *referral from health authorities to assessment time within six weeks*



13.2.6 Appeals System

The Task Force recommend (Chapter 4) that the Department of Education and Science establish an **Independent Review Body**, in keeping with the *Report of the Planning Group: A National Support Service for Special Education for Students with Disabilities* (2000) recommendations, to intervene in cases when provision is disputed. Such an appeals body should act in response to the needs of the child and young person and make recommendations that reflect the primacy of the child's needs. The Task Force suggests further that the appeals system endorse mediation as the preferred method of resolving disagreement or disputes between parents and statutory bodies.

Independent Appeals Body suggested process

Timing:

- Stage 1** *acknowledgement of appeal initiated within two weeks*
- Stage 2** *informal hearing and mediation within a further two weeks*
- Stage 3** *formal arbitration by a third party within a further two weeks*
- Stage 4** *formal Review hearing and written, legally binding, response within a further two weeks*

In the event of an appeal of a draft statement of need based on the multi-disciplinary assessment, the Task Force recommends that the person with an ASD remain in an interim placement pending the outcome of the appeal. No person should be deprived of an education for any length of time because of a difference of opinion between adults. Internationally, there are many models of effective and equitable independent appeals systems. The Task Force recommends that the model adopted by the Department of Education and Science incorporate the following elements:

- Accessibility
- Independence
- Speedy processing and resolution (well within the *maximum* timeframes above)

- Parental advocacy

The members of the Appeals Board should:

- Be independent
- Have knowledge and understanding of the difficulties associated with ASDs.

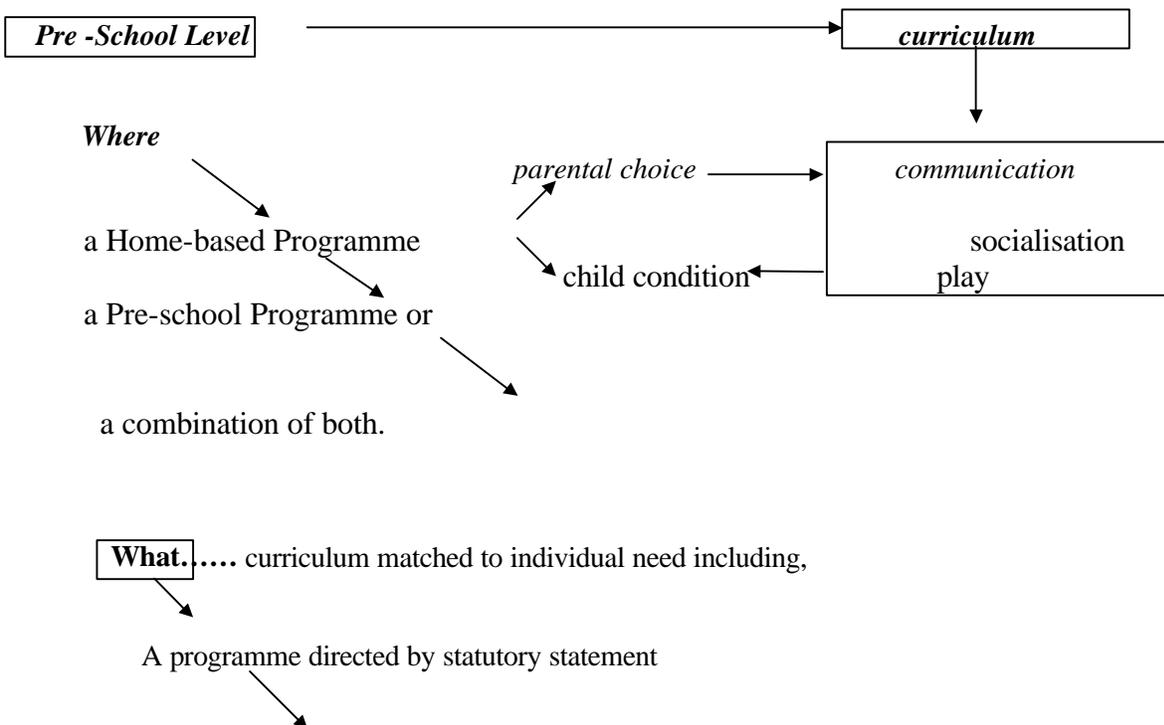
13.2.7 Review of Progress

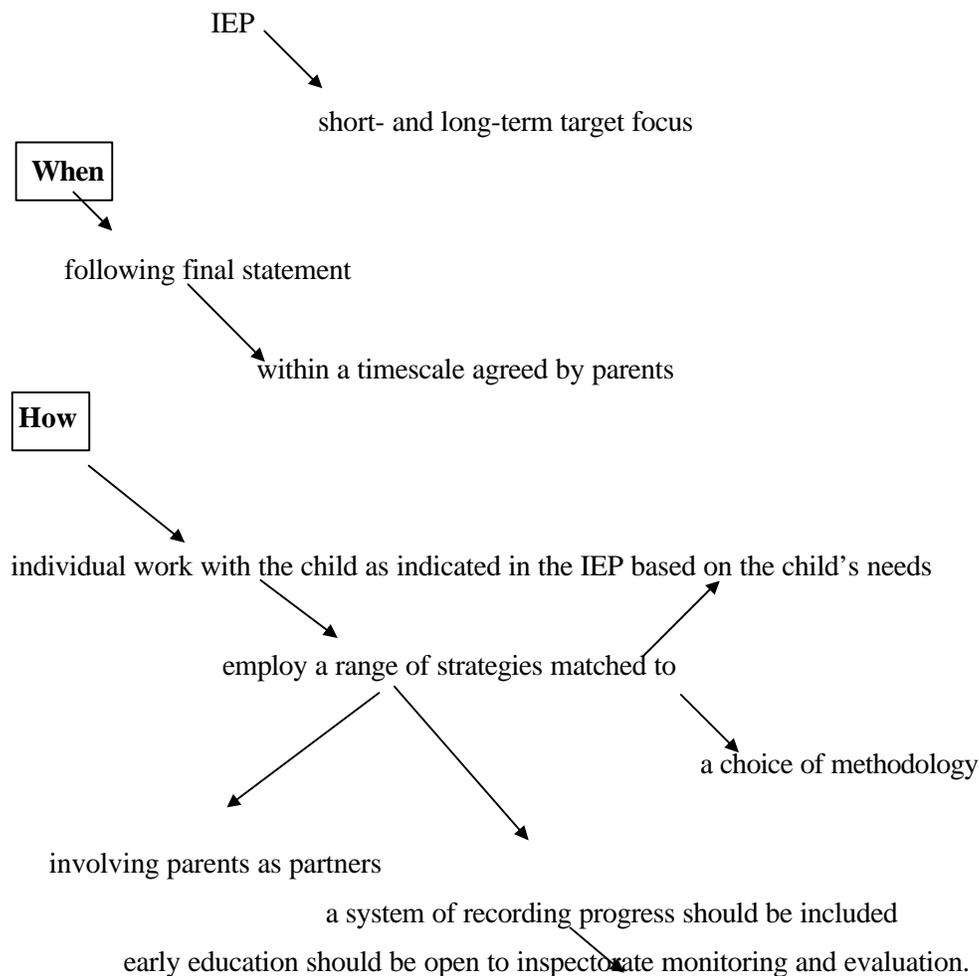
It is the view of the Task Force that Statementing procedures should have an in-built review process. This should contain, *inter alia*, the following elements:

- An annual review of the Statement of Need by service providers, which would be recorded by the regional Special Needs Organisers (or by the Inspectorate, pending the establishment of the regional Special Needs Organisers);
- The IEP (which is an organic, developmental instrument) should be reviewed on a continuous basis;
- A multi-disciplinary transition review to effect transfer to second level, initiated by Special Needs Organisers
- An end of second level transition review to effect post-second level placement

13.2.8 Range of Provision

13.2.8.1 Early and Pre-School Education

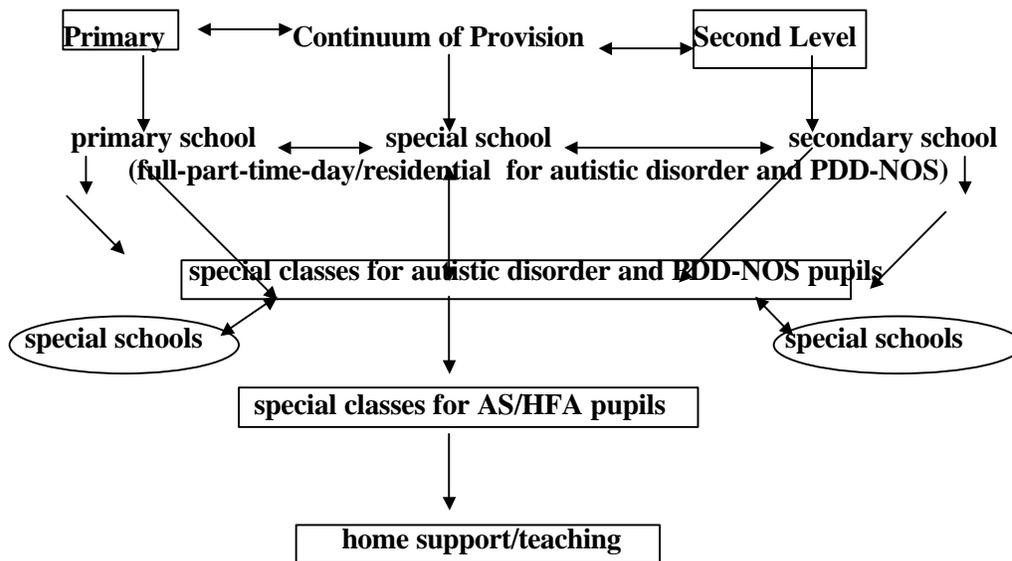




To provide the forms of early education and pre-school provision recommended by the Task Force in Chapter 7, the Department of Education and Science and Health Boards who will apply agreed criteria and provide ongoing monitoring of the provision, facilitated jointly by the Department of Education and Science Special Needs Organiser and the Department of Health ASD Co-ordinator. A considerable expansion of pre-school provision for children with ASDs will be required in home-based, special and mainstream settings. It is the view of the Task Force that the Department of Education should take responsibility for early and pre-school education for children with ASDs, and that its Inspectorate, in collaboration with that of the Department of Health and Children, should provide the monitoring and evaluation function. This work could be done in collaboration with the new Centre for Early Childhood Development and Education, announced in September 2001, whose role will be to develop quality standards for early childhood education. A key function of this new Centre, as announced, will be to examine and develop forms of early intervention and support for children from disadvantaged backgrounds and children with disabilities, building on the

experience of existing programmes (press release from Minister for Education, 27 September 2001). Approval for grant funds to support pre-school centres or groups must be sought from, and sanctioned by, the Inspectorate personnel of the Department of Education and Science and Health Boards who will apply the agreed criteria and provide ongoing monitoring of the provision.

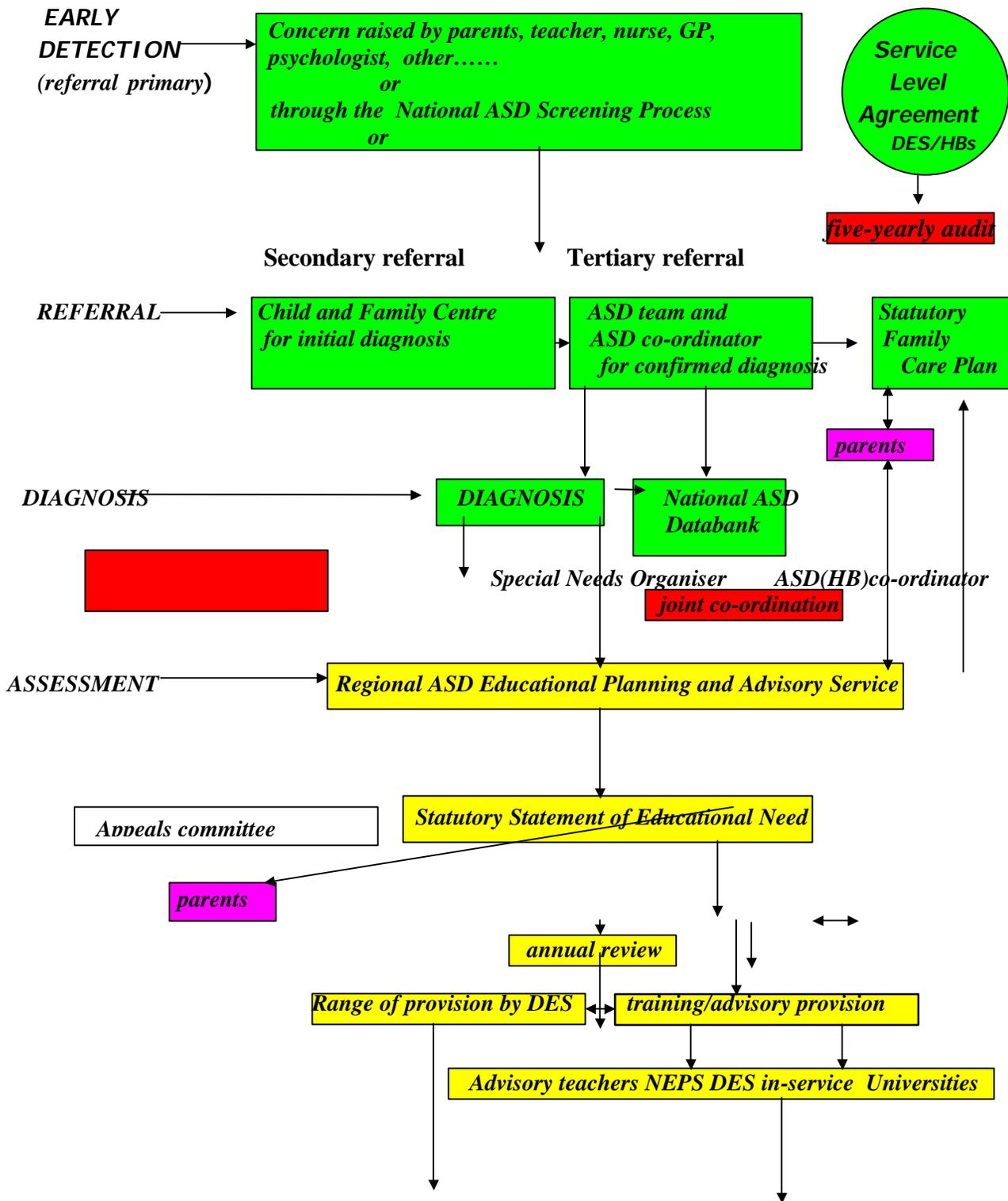
13.2.8.2 Primary and Second Level Provision: continuum of provision with primacy given to mainstream placement with support

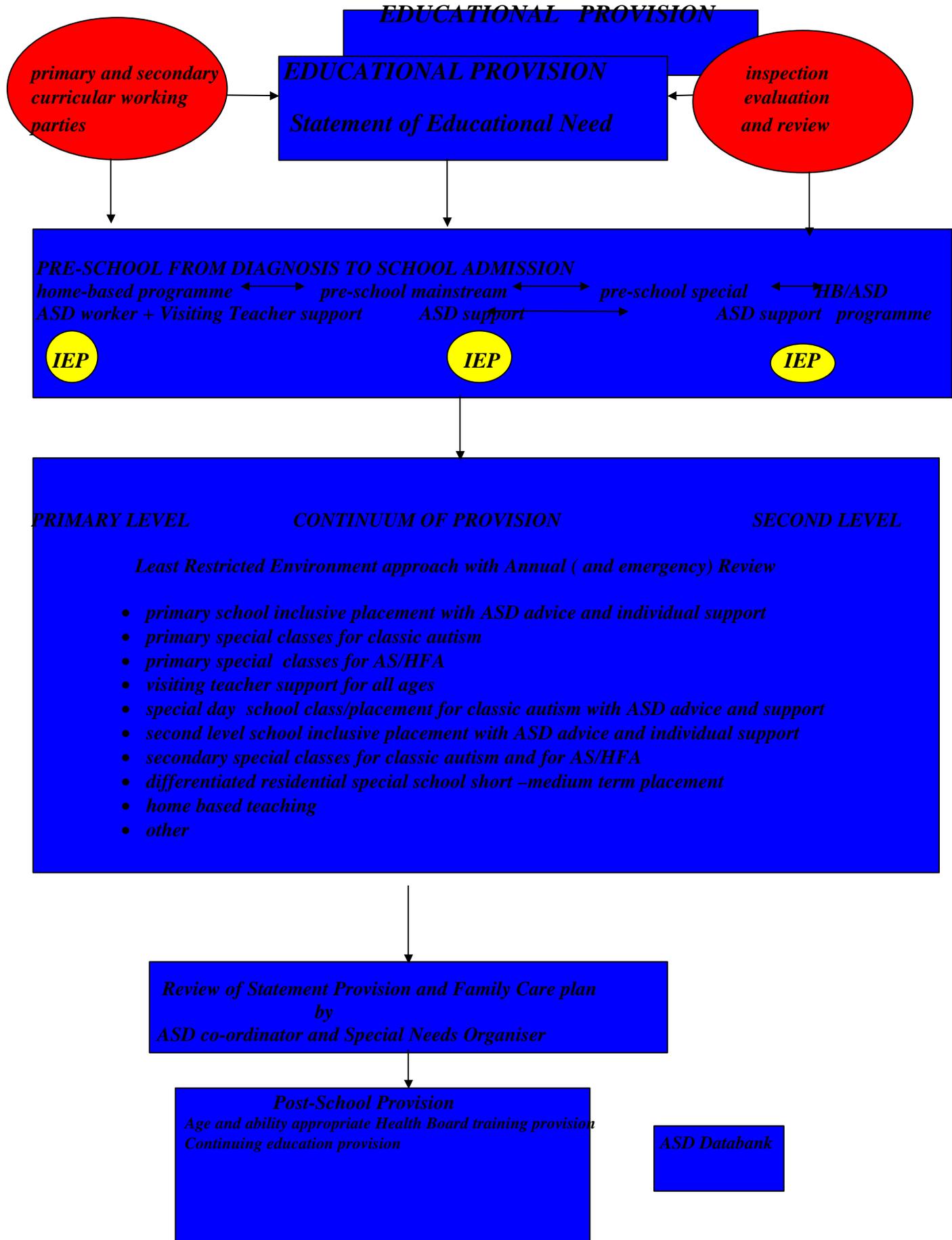


13.2.8.3 Post-school Provision

In the post-school phase, it is critical that there is age- and ability-appropriate educational provision, and supported employment initiatives, for persons with ASDs. As the Task Force has indicated throughout this report, autistic spectrum disorders are highly complex and persons so affected range greatly in abilities and needs. Historically, the needs of those with Asperger syndrome have inappropriately been equated with those associated with general intellectual disability or classic autism. It is important that state agencies, such as the Health Boards and FAS, and further and higher educational institutions, be encouraged to develop an awareness of the unique needs of each of the groups on the autistic spectrum. If reforms in education are to result in lifelong improvements for persons with ASDs, and their families, it is vital to ensure that the necessary follow on supports are available in adulthood. Reports in the United Kingdom, cited in Chapter 10 of this Report, have highlighted the problems experienced by the ASD group in adulthood and have suggested that the gains of education in childhood may be reversed in adulthood if there is an absence of continuing education, training, and ongoing support and assistance to take up and retain employment.

13.2.8.4 OVERVIEW OF PROVISION OF SERVICES: STRUCTURES





Employment open/sheltered/supported for AS/HFA
Other (e.g. HEIs for AS/HFA)



The Task Force recommends that administrative, co-ordinating and funding arrangements be established by the Department of Education and Science, in collaboration with the Departments of Enterprise, Trade and Employment and the Department of Health and Children, to provide for the proposed structures for the implementation of educational/training/supported employment provision and support systems for persons with ASDs proposed in this Report.

13.2.9 Curriculum Development

To support the proposals on appropriate curriculum at the various educational levels made in Chapters 8, 9 and 10, the Task Force recommends the establishment of Primary, Second level and Post- second level Curriculum Working Parties to make detailed recommendation on the curricular/vocational content and strategies to enable teachers and others to meet effectively the needs of pupils attending primary and secondary, including special, schools and continuing education colleges or training facilities. The Task Force identifies initial areas for consideration within the remit of the curriculum parties:

Curriculum to include:

- *programme access guidelines*
- *individualised ASD programme guidelines*
- *use of NCCA guidelines*
- *general ASD strategies*
- *personal and social programme for all pupils highlighting the differing needs of sub groups on the autistic spectrum*
- *support strategies, circle of friends, buddying (with parental permission)*
- *behavioural strategies/guidance (if behavioural difficulties have been identified)*
- *resource implications*
- *vocational and training guidelines*

13.2.10 Inspection and Evaluation

The Task Force proposes that the Department of Education and Science establishes, through its Inspectorate Services, a system to evaluate ASD provision, and that it collaborates, as appropriate, with the Department of Health and Children in such evaluation (particularly in Early Education provision). The Task Force note the following issues as important to assist the development of an appropriate evaluation system. These include:

- the need for ASD service providers, including mainstream schools, to be accountable to parents for the quality of provision made for their children and young people;
- the need to make information about the quality of ASD provision available generally to allow good provision to be celebrated and weaknesses addressed;
- the need to develop ASD provision performance indicators and criteria to monitor, evaluate and improve the standards achieved by the children and young people;
- the need to inform training programmes which can contribute to effectiveness and improvement;
- the need for a cycle of evaluation, including a baseline assessment;
- the need to inform the Department of Education and Science and Health Boards, and the government, of the impact of the service on meeting the stated aims of the provision;
- to need to ensure value for money.

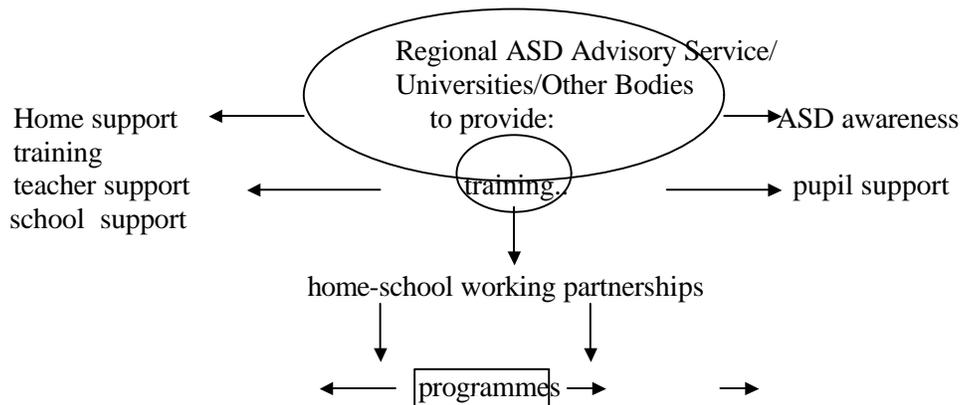
The Task Force recommend that Inspection requirements should be designed to include,

- members of the Inspectorate trained in ASDs
- a Department of Education and Science booklet on Evaluating ASD provision/ASD Education Handbook
- inspection protocols and procedures issued to service providers
- parental views sought and included in inspection reports
- Inspectorate-school partnership ethos and approach
- summary of inspection findings available to parents.

13.2.11 Advisory and Training Support Service

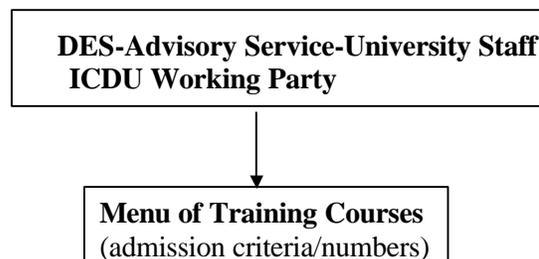
The Task Force recommends, in Chapter 3 that the role of Partnership Facilitator be created and located in the office of the regional Special Needs Organiser to facilitate good communication between home and school and to provide support for parents. Although Partnership Facilitators would be based in the office of the Special Needs Organiser they would spend a majority of their time in their assigned schools and liaising with families. Their primary allegiance would be to advocate for the persons with ASDs. They would ensure good two-way communication between school and home. They would also be in frequent liaison with the teachers (mainstream and special needs) and classroom assistants, school principal, Visiting Teacher for ASDs (recommended in Chapter 5), visiting clinicians, and any other support personnel involved in the school. The role should also include close liaison with the Health Board ASD Co-ordinator to ensure that the proposed Child and Family Support Plan is properly effectuated.

In Chapter 5, the Task Force recommends that the Department of Education and Science should devise a Visiting Teacher for ASDs Advisory Service whose task it will be to provide practical help, training and advice to parents, schools and pre-school providers, and where appropriate to the children and young people themselves. This latter service can be created by the appointment, as autistic spectrum disorders advisors, of a group of Visiting Teachers to supplement the work of the Regional Autistic Spectrum Disorder Educational Planning and Advisory Service under the administrative and management control of the Regional Special Needs Organiser. The In-Career Development Unit of the Department of Education and Science are likely to play a crucial role in the development of this services, and should carry out this role as part of the process of educating key personnel to act as advisors, and to support the formation of *Individual Education Plans* (IEPs) as detailed in Chapter 5. The in-career development and training of these key personnel will be of particular importance. Visiting Teachers should be educated to understand the differences and difficulties associated with ASDs, and in an awareness of the differing needs of students with classic autism and Asperger syndrome, as well as in the range of ASD-appropriate educational interventions. Teachers will need to be aware that a 'one size fits all' approach will not adequately address the needs of a group whose disabilities range from profound intellectual disability to very high intellectual functioning.



The universities should be invited and resourced, by the Higher Education Authority, to introduce accredited ASD modules within undergraduate and post-graduate programmes for the various categories of professional staff identified in this Report, most particularly in Chapter 12. Where relevant, on professional programmes, such provision should meet the professional accreditation standards of the appropriate bodies and should be recognised by the Department of Education and Science and, when operational, the Teaching Council. The Task Force, in addition, proposes that, as the National Educational Psychology Service expands, named psychologists in each region should develop a special interest in autistic spectrum disorders, in assessment and approaches to intervention, and should be available to support schools and the advisory service in their work.

The In-Career Development Unit of the Department of Education and Science should establish a working party to initiate and support the expansion further of localised/accredited training for teachers specialising in ASDs.



Such action should come into force within a three-year period.

13.2.12 Administrative Support at the Department of Education and Science

The Special Education Section in the Department of Education and Science administers provision and arrangements for students with special educational needs at both primary and post-primary level. It is the view of the Task Force that the Department of Education and Science should take overall responsibility for early and pre-school education for children with ASDs. This will necessitate some changes and increases in staffing within the Special Education Section to accommodate this widened responsibility. In Chapter 15 it is pointed out that one of the conclusions arising from the Department of Education and Science - *Review of Department's Operations, Systems and Staffing Needs*, 2000 (The Cromien Report) is that the Department of Education has found it more difficult to focus on such functions as policy analysis and strategic planning because of its administrative workload and that it is modestly staffed compared to many other Departments, with around 900 staff - compared, for example, to about 4,000 in the Department of Agriculture.

The Task Force also feels that the establishment of a separate Post-Primary Special Education Section would greatly facilitate the targeting of appropriate resources to students with ASDs, as well as students in other disability categories at second level.

In Chapter 14 the Task Force puts forward its view that legislative as well as administrative reform is required. It endorses the establishment of the National Council for Special Education, and the establishment of regional Special Needs Organisers and the setting up of an independent appeals structure. The Task force further recommends that a Disabilities Civil Rights Section should be established within the Department of Education and Science with overall responsibility for policy formulation in relation to educational rights for people with disabilities, and it recommends that Regional Resource Centres be established in the offices of the Special Needs Organisers, to equip parents with the means by which they can make the best use of the system of rights provided for by the Act proposed in Chapter 14. Decisions already taken, and recently announced, by the Department of Education and Science, and the additional structures, provision and support services recommended in this Report, will create a need for significant numbers of new staff within the Department of Education and Science and in the new bodies to be established.

The Task Force is aware that present staff levels within the Department of Education and Science are inadequate for the implementation of existing policy developments within special education, and for the speedy processing of applications for support for children with special needs (including ASDs). The Task Force therefore recommends that additional staff be recruited for the

Department of Education and Science Special Education Sections and for the new agencies as soon as possible, and trained as appropriate.

13.3 FUNDING THE REFORM OF EDUCATIONAL PROVISION AND SUPPORT SERVICES FOR PERSONS WITH ASDs

In proposing the radical reform of educational provision and support services for persons with ASDs, some of which will inevitably extend to other persons with disabilities and special educational needs, the Task Force is aware that the costs to the Exchequer will be significant. The increase in costs will derive not only from the establishment of structures, entitlements, supports and training requirements outlined in this Chapter and throughout the Report but from the increases in diagnosed cases of autistic spectrum disorders which will almost inevitably take place. Research cited in this Report from Ireland and from other countries indicates that the incidence of autistic spectrum disorders is on the increase. Increased awareness of the condition among parents and professionals, screening, and improved diagnostic techniques will also add to the numbers of diagnosed cases. It is imperative that the relevant Departments of state take cognation of these trends, and of the legitimate demands of parents and advocates for clear entitlements and adequate levels of service, and plan accordingly.

The increases in outlay which will be required to implement the recommendations of this Report are in direct relationship to the level of under-investment which has characterised this sector until now. There has, in recent times, been a growing public awareness of the need for substantial investment in the education of persons with ASDs. In the judgments in both the O'Donoghue and Sinnott High Court cases (see Chapter 14) there was a recognition of the failure of the State to make appropriate provision for children with disabilities and special educational needs. The current Minister for Education and Science has signalled his intention to increase expenditure to compensate for past inadequacies of provision and has made mention of the availability of a 'blank cheque' from Government to tackle the outstanding issues. In a Press Statement in early September 2001 (4.9.01) the Minister stated that annual expenditure on providing facilities for special needs pupils has increased from £7 million to £70 million per year and that the figure is rising monthly as additional needs are assessed and new 'state-of-the-art dedicated facilities' are being established. The Task Force welcomes this openness to increasing expenditure on this under-resourced area and it recommends that estimates to address the predicted increase in incidence, and the recommendations for educational provision and support services for persons with ASDs, contained in this Report are fully costed and included in the annual budgetary allocations for the Department of Education and Science (and for other Departments of state providing support services), with effect from the next financial year. As the Task Force argues in Chapter 16 of this Report on the costs and benefits of educational intervention for persons with an ASD, while there may be increased costs in the

short term these will result in long term savings to the Exchequer as the levels of dependency of this population decrease. There is also a very high return on such investment in terms of social costs and benefits, since increased investment will lead to an improved quality of life for persons with ASDs and their families. Increases in Exchequer spending to provide appropriate education and support for persons with autistic spectrum disorders (and indeed for persons who have other disabilities and special educational needs) will also fulfil Ireland's commitments and obligations under the Constitution and under international conventions and agreements ratified by Ireland.

13.4 Recommendations

The Task Force recommends:

Policy

- 1 that an Inter-Departmental ASD Working Group be established as a sub-committee of the existing Inter-Departmental Co-ordinating Committee between the Departments of Education and Science and Health and Children; that its general remit include the production of a Service Level Agreement to indicate clearly the responsibility, including resources, of each Department, to secure and to implement educational provision and support services for persons with ASDs; that the recommendation in Chapter 15 of this Report - that the announced inter-Departmental team of high-level officials to co-ordinate response to the needs of children with autism be established and that it co-ordinate responses to the needs of all children with an ASD; and that it be given responsibility for overseeing the implementation of the recommendations of this Report – be implemented;**
- 2 that at regional level a Regional Autistic Spectrum Disorder Educational Planning and Advisory Service be created, under the joint authority of the Department of Education and Science and the National Council for Special Education, administered and managed by a Regional Special Needs Organiser, and supported by a multi-assessment planning team, to identify and secure effective provision for children with ASDs within a Statutory Statement of Educational Need; that this Regional Autistic Spectrum Disorder Educational Planning and Advisory Service be established within each Health Board region, and work in formal collaboration with the Health Board ASD Intervention Services facilitated by the Health Board ASD Co-ordinator, so as to ensure the automatic delivery of the necessary support services;**

- 3 that, as an interim measure, and until such times as independent diagnostic services, as recommended by the Task Force, have been agreed and implemented, the current Health Board arrangements (including whatever ASD Services are available, facilitated by the newly established post-holders for ASD co-ordination within the Health Boards) convey the details of the ASD diagnosis, and the impact of the diagnosis on the child's or young person's ability to learn and to socialise, in order to assist the Department of Education and Science Inspector, and the multi-disciplinary team to identify appropriate interventions and supports for persons diagnosed with an ASD;**
- 4 The Task Force recommend that the Department of Education and Science establish an Independent Review Body, in keeping with the *Report of the Planning Group: A National Support Service for Special Education for Students with Disabilities* (2000) recommendations, to intervene in cases when provision is disputed; that the appeals system endorse mediation as the preferred method of resolving disagreement or disputes between parents and statutory bodies; that, in the event of an appeal of a draft statement of need based on the multi-disciplinary assessment, the child remain in an interim placement pending the outcome of the appeal; that the model adopted by the Department of Education and Science be accessible, independent and speedy, operating within the *maximum* time frames recommended in this Report; that the members of the Appeals Board be independent and have expertise in ASD appropriate education;**
- 5 that Statementing procedures have an in-built review process;**
- 6 that administrative, co-ordinating and funding arrangements be established by the Department of Education and Science, in collaboration with the Departments of Enterprise, Trade and Employment and the Department of Health and Children, to provide for the proposed structures for the implementation of educational provision, training and supported employment, and support systems, for persons with ASDs proposed in this Report;**
- 7 that Primary, Second level and Post- second level Curriculum Working Parties be established to make detailed recommendation on the curricular/vocational content and strategies to enable teachers and others to meet effectively the needs of pupils attending primary and secondary, including special, schools and continuing education colleges or training facilities;**
- 8 that the Department of Education and Science establish, through its Inspectorate Services, a system to evaluate ASD provision;**

- 9 that the In-Career Development Unit of the Department of Education and Science establish a working party to initiate and support the expansion further of localised/accredited training for ASDs; that the In-Career Development Unit, and relevant courses in universities, be resourced to provide the appropriate education and training programmes to enable staff to meet the educational needs of persons with ASDs;**

- 10 that the Department of Education and Science take overall responsibility for early and pre-school education for children with ASDs; that a separate Post-Primary Special Education Section be established within the Department; that a Disabilities Civil Rights Section be established within the Department of Education and Science with overall responsibility for policy formulation in relation to educational rights for people with disabilities; that Regional Resource Centres be established in the offices of the Special Needs Officers, to equip parents with the means by which they can make the best use of the system of rights provided for by the Act proposed in Chapter 14; that additional staff be recruited for the Department of Education and Science Special Education Sections and for the new agencies as soon as possible, and trained as appropriate;**

- 11 that estimates to address the predicted increase in incidence, and the recommendations for educational provision and support services for persons with ASDs, contained in this Report are fully costed and included in the annual budgetary allocations for the Department of Education and Science (and for other Departments of state providing support services), with effect from the next financial year.**

CHAPTER 14

EDUCATION FOR CHILDREN WITH AN ASD - CONSTITUTIONAL AND LEGISLATIVE ISSUES

14. INTRODUCTION

This Chapter begins with an outline of two High Court cases. The judgements in these can be regarded as substantially giving the current position concerning an understanding of the kind of education service to which children with severe disabling conditions, such as Paul O'Donoghue and Jamie Sinnott, are entitled to under the constitution. It also includes a summary of the outcome of the State's appeal to the Supreme Court in the Sinnott case. Reference is made to difficulties in interpreting constitutional intent regarding educational rights and recommendation are put forward to assist in addressing these. This Chapter also addresses a range of issues relating to legislation as it affects persons with disabilities, including autistic spectrum disorders and makes recommendations accordingly.¹

14.1 THE CURRENT POSITION

14.1.1 The Constitution of Ireland

The Constitution makes special provision for the education of children. Article 42 provides for the rights of parents as the primary and natural educators of their children, the right of children to receive a certain minimum education and the duty of the State to ensure that that right is respected, and generally to provide for free primary education. While the State is under an obligation to provide for free primary education and should ensure that such a service is available, parents may avail of the service thus provided or may choose to have education provided for their children by other means.

14.1.2 The O'Donoghue High Court Case

14.1.2.1 Background

In 1983, a report entitled *The Education and Training of Severely and Profoundly Mentally Handicapped Children in Ireland* recommended that children with severe and profound mental handicap have access to teachers paid and supervised

¹ The Task Force gratefully acknowledges the advice so generously given on constitutional and legislative issues by Professor Gerard Quinn and Ms Shivaun Quinliven of the Disability Law and Policy Research Unit, Faculty of Law at the National University of Ireland, Galway. The Task Force benefited greatly from this advice but also acknowledges that any errors contained in this Chapter are those of the Task Force.

by the then Department of Education. A four-year Pilot Scheme was established in January 1986. There was a delay, however, in making the service generally available to all such children and the quality of the service provided under the Pilot Scheme was considered by many to be inadequate. In 1992 legal proceedings were instituted by his mother seeking, by way of judicial review in the High Court, to compel the Minister for Education to provide Paul O'Donoghue, a child then eight years of age and with profound general learning disability, with free primary education. His mother was not satisfied with the arrangements which were subsequently made for his education and in 1993 proceeded with a case in the High Court - *O'Donoghue v. the Minister for Education (et al)* with a view to vindicating the constitutional right of her son to free primary education.

14.1.2.2 Judgement

Mr. Justice O'Hanlon gave judgement in favour of the applicant by making an Order declaring that the State had deprived him of constitutional rights:

- i) in failing to provide for free primary education;

(In the course of his conclusions the Judge adopted the definition of education by O'Dalaigh C.J. in *Ryan v. The Attorney General [1965] I.R. at p.350*:

Education essentially is the teaching and training of a child to make best possible use of his inherent and potential capacities, physical, mental and moral

and stated:

I conclude, having regard to what has gone before, that there is a constitutional obligation imposed on the State by the provisions of Article 42, S. 4 of the Constitution to provide for free basic elementary education of all children and that this involves giving each child such advice, instruction and teaching as will enable him or her to make the best possible use of his or her inherent and potential capacities, physical mental and moral, however limited these capacities may be(p 39).

- ii) and in discriminating against him as compared with other children.

(The Judge spoke of '... a constitutional obligation on the part of the State to provide for free primary education for this group of children in as full and positive a manner as it has done for all other children in the community').

In reviewing the evidence Mr. Justice O’Hanlon stated that:

- a) he was convinced that a much greater deployment of resources was required than was thought appropriate when the Blue Report was completed, he believed that the arrangements made under the Pilot Scheme were not sufficient to meet the State’s obligation under the Constitution;
- b) the evidence gave rise to a strong conviction that a new approach was required for this category of children regarding:
 - age of commencement: early intervention and assessment being of vital importance;
 - duration of primary education: the process should, ideally, continue as long as the ability for further development is discernible – age 18 may not be unrealistic;
 - continuity of education: the teaching process should, as far as practicable, be continuous throughout the period of primary education.

14.1.2.3 Appeal to Supreme Court

The judgement was appealed to the Supreme Court on an issue of principle, i.e. that the High Court had improperly intervened in the exercise by the Government of its executive functions arising from the opinions expressed by the Judge in the course of his review of the evidence. The Supreme Court was not disposed to the view that there were issues of principle in the High Court judgement which required adjudication by it. On being informed that both parties were satisfied that the applicant was by then (6.2.97) receiving an education appropriate to his condition, the Supreme Court found that there was no longer an issue between them and substituted for the declaration of the High Court a declaration that:

the infant plaintiff is entitled to a free primary education in accordance with Article 42.4 of the Constitution and the State is under an obligation to provide for such education.

14.1.3 The Sinnott High Court Case

14.1.3.1 Background

The O’Hanlon judgement of 1993 in the O’Donoghue case regarding Pupil Teacher Ratio and provision of Special Needs Assistants was not implemented until 1998. Jamie Sinnott was born on 11 October 1977. In his review of the evidence Mr. Justice Barr stated that Jamie Sinnott suffered since infancy from profound mental

disablement, physical disablement and severe autism. By the time he had reached twenty-three years of age he had received less than three years of meaningful education and training. His mother's solicitors had been in correspondence with the Minister for Education in the course of the school year 1994/95. In December 1996 they proceeded with a case in the High Court - *Jamie Sinnott v. the Minister for Education and others* with a view to vindicating the constitutional right of her son to free primary education and to establishing whether there was an age limitation on the constitutional right to a free primary education.

14.1.3.2 Judgement

Mr. Justice Barr delivered his judgement in the High Court on 4 October 2000. Jamie Sinnott was then twenty-three years of age. In relation to the State's constitutional obligations, Mr. Justice Barr stated:

- i. *... the constitutional obligation to provide primary education, training and health care for the plaintiff and others like him is that of the State per se;*
- ii. *A citizen's constitutional right must be responded to by the State in full. A partial response has no justification in law, even in difficult financial circumstances ...(p 27)*

Mr. Justice Barr adopted the definition of education of O'Hanlon, J. in the O'Donoghue case. He also stated that:

In my opinion the ultimate criteria in interpreting the State's constitutional obligation to provide for primary education of the grievously disabled is 'need' not 'age'.

Mr. Justice Barr referred to:

- i. *the conscious deliberate failure of Finance administrators to pay due regard to and take effective steps to honour the obligations of the State to Jamie Sinnott on foot of the O'Donoghue judgement ... (Government approval (for a PTR of 6:1 and provision of child care assistants) was ultimately granted on 29th October, 1998 - more than five years after the judgement in O'Donoghue)*
- ii. *the apparent lack of appreciation by the State of the basic problems associated with severe autism and related disabilities since there is no evidence to suggest that any decision has been made at departmental or government*

level even yet about the provision of any ancillary services for sufferers from severe autism (e.g. speech, occupational and physio therapies and general health care) which are fundamental to their education and training.

He found that the State's breach of duty included a substantial list of factors. These are given in Appendix 17. Mr. Justice Barr concluded that a twofold weakness in the state administrative structure gave rise to the plaintiff's claims:

- i. *insufficient liaison between Departments of State where a particular problem involves two or more of them; and*
- ii. *the administrators in the Department of Finance ... appear to be insufficiently informed regarding the constitutional obligations of the State to the weak and deprived in society to enable them to assess realistically the degree of priority which should be attached to each such claim and the structure of priority which the State should devise in meeting its constitutional as distinct from its non-constitutional obligations (p 26).*

The Justice found that:

both plaintiffs are entitled to the declarations which they claim in their respective Statements of Claim (i.e. mandatory declarations) and to damages arising out of breach of their constitutional rights, negligence and breach of duty by the State in that regard.

Damages in the amount of £200,000 were awarded to Jamie Sinnott and in the amount of £55,000 to his mother, Kathryn Sinnott. The Justice directed that the case be reviewed in April 2003.

14.1.3.3 Appeal to the Supreme Court

On 31.10.2000 the Government lodged an appeal to the Supreme Court with a view to clarifying points of law. The hearing commenced on 27.3.01 before the Chief Justice, Mr. Justice Keane and Ms. Justice Denham, Mr. Justice Fennelly, Mr. Justice Geoghegan, Mr. Justice Hardiman, Mr. Justice Murphy and Mr. Justice Murray. Judgement was delivered on 12.7.01. The Supreme Court:

- found that the State's constitutional obligation to provide for free primary education applies to children only, not adults, and ceases at the age of 18.
- revoked the mandatory orders made by Mr. Justice Barr in the High Court and substituted a formal declaration that the State, in failing to provide for

free primary for Jamie Sinnott up to the age of 18 and appropriate to his needs, had deprived him of his constitutional rights.

(In the High Court, Mr. Justice Barr had prescribed in detail what an educational programme for Jamie Sinnott should involve and made a mandatory order regarding its provision. The Supreme Court found that this mandatory order contravened the constitutional doctrine of the separation of the powers of the legislative, executive and judicial arms of the State.)

- upheld the State's appeal against the High Court finding that Mrs. Sinnott's constitutional rights had been breached as a result of its failure to vindicate her son's constitutional right to free primary education.

(The State is not now obliged to pay the £40,000 awarded by the High Court in general damages to Kathryn Sinnott. The State has, however, undertaken to pay Jamie Sinnott and his mother the full amount of the damages awarded by the High Court, including an exgratia payment of £40,000.)

14.2 REVIEW

14.2.1 REVIEW OF CONSTITUTIONAL ISSUES

The Constitution is the basic law of the State. The provisions of Article 42 require the State to provide for free primary education up to the age of eighteen years. The High Court has a duty under the Constitution to secure, vindicate and enforce the constitutional rights of citizens. However, as the terms used in the Constitution are not defined, the actual text used does not make constitutional intent clear regarding what it construes by the terms *education* or *primary* or the entitlements of citizens or the obligations of the State in relation to these. Higher Court judgements or legislation are required as a means of providing an operational specification of constitutional intent. A number of laws have been enacted in recent years which bring greater clarity to the constitutional rights of citizens in relation to education - these are outlined in Appendix 18 and include the *Education Act 1998* which is reviewed later in this Chapter.

The *Education Act 1998*, however, does not deal in a specific way with many of the issues regarding education for children with disabilities. The question of the arrangements, procedures and structures through which a level and quality of education appropriate to meeting the needs and abilities of children with severe disabling conditions, such as autistic spectrum disorders, is not addressed. For many parents of children with autistic spectrum disorders, clarification of constitutional entitlements regarding the education of such children means a judicial review in the High Court.

14.2.2 REVIEW OF THE HIGH AND SUPREME COURT JUDGEMENTS

O'Donoghue v. the Minister for Education. and others and *Jamie Sinnott vs. the Minister for Education and others* are two landmark cases, contributing to a fuller understanding of the constitutional obligation of the State concerning educational provision for children with severely disabling conditions. The significance of these cases rests on a number of factors, e.g.:

- i. The judgements confirmed that there could be a substantial difference between the education service that a child with a disability was entitled to under the provisions of the Constitution and the education service that the State had provided. Some nineteen shortcomings are listed in the Barr judgement in the Sinnott case;
- ii. The judgements found that there was insufficient understanding on the part of the State that a constitutional right must be responded to in full and that such a right carries with it an obligation on the State to put the resources and arrangements in place to do so;
- iii. That the High Court found it necessary to state that children with disabilities are entitled to have an education, which is as well suited to their needs and abilities as the education, which is generally provided, is for their non-disabled peers;

[This was in a context where it had been put forward as long ago as 1971 by the then Department of Education that "*each child ... deserves to be ... provided with the kind and variety of opportunities ... towards stimulation and fulfilment which will enable him to develop his natural powers at his own rate to his fullest capacity*" (*Primary School Curriculum, Teacher's Handbook*, part 1, p 13).]

- iv. With regard to the question of the level and quality of education appropriate to meeting an applicants' needs and abilities, the High Court adopted a stance that was based on professional assessments and was in line with the recommendations put forward in the Report of the Special Education Review Committee (1993) - i.e. the Courts generally drew on sources of information equally available to the Department.
- v. The Judge set out in some detail what the Court considered to be the essential elements of primary education for the Plaintiff.

In summary:

- The High Court, having regard to expert evidence provided to it, decides whether or not the education provision made for a child vindicates his or her constitutional right to free primary education.
- Where the High Court decides that the constitutional requirements are not met, it has in many cases sought to set down what the State must do in order to meet its obligations in respect of the provision for free primary education. The Supreme Court has ruled in the Sinnott case that the use of a mandatory order in such situations breaches the principle of separation of powers. A declaratory order would not do so. It would leave to the executive and legislative arms of the State responsibility for taking whatever action was appropriate to vindicate the constitutional rights of a successful High Court applicant.
- On the other hand, those who argue for a more interventionist approach by the Courts say that this is necessary to ensure that State bodies take appropriate action.

14.3 THE NEED FOR CONSTITUTIONAL REFORM

In its submission to the Constitutional Review Group in 1995, the Commission on the Status of People with Disabilities asserted that the right to an education is absolutely foundational in a liberal democracy. The submission argued that a concern for equality in education leads inevitably to a concern to ensure that there is a continuum of placements designed to be inclusive of one another, rather than starkly opposed as hitherto; that there is adequate support in material and human resources; that there is a right to be placed in the least restrictive environment; that there is a right to be paced in a school that is reasonably proximate in geographic terms. These are all *substantive* issues that implicate both the right to equality (Article 40.1) as well as the right to education (Article 42). There is now, they contended, a need to reformulate the right to education to emphasise, inter alia, its substantive character (Commission on the Status of People with Disabilities, 1995). The Task Force commends these arguments in any future consideration of constitutional reform.

In Chapter One of this Report, the Task Force quoted in full Article 13 of the UN *International Covenant on Economic, Social and Cultural Rights*, which Ireland has ratified and which is binding on the State. One outcome of its binding nature is that the State must periodically report to the UN on its implementation. In 1999, in its Concluding Observations on Ireland's Report, the relevant UN committee concluded that the equality provision in our Constitution was inadequate to meet the relevant non-discrimination provisions under the Covenant (Quinn, 2001). For example, the deficiencies were shown up in the 1997 decision of the Supreme Court in striking down the disability parts of the

Employment Equality Bill. The UN committee also specifically referred to the lack of legislation dealing with the rights of the mentally handicapped (ibid.).

In the light of the demands of citizens, of international covenants and agreements which Ireland has ratified, of the comments of the UN on Ireland's implementation of *the International Covenant on Economic, Social and Cultural Rights*, of submissions made by the Commission on the Status of People with Disabilities to the Constitution Review Group, and of the Court judgements outlined above, the Task Force is of the view that there is a need for Constitutional reform. The Task force recommends that the Government pay urgent attention to the need for such appropriate constitutional reform to provide clearer provision for the rights of persons with disabilities to education and to provide a more solid legal basis for advanced legislation in the field.

The Task Force recommends that the constitutional right to education should not be taken in isolation but should be viewed against the over-arching right to equality. It is the interaction between the two rights when taken together that should drive the process of legislative reform forward. Therefore, and in order to further strengthen the right to education, the Task Force recommends that the right to equality should also be considerably strengthened. It commends the arguments and practical proposals for such change as put forward by the Commission on the Status of People with Disabilities in its submission to the Constitution Review Group.

The Task Force recommends that the constitutional right to education should be reformulated to concentrate more on the substantive right itself. It considers it imperative that the main emphasis in any reformulated right should be the right to an *equally effective* education for all, regardless of difference. Hence the organic link between equality and education. The Task Force commends Article 13 of the *International Covenant on Economic, Social and Cultural Rights* (see Chapter One) as a good departure point since it makes it plain that the basic right that is at stake is to 'basic learning' for all, which includes adults. The Task Force also recommends the arguments and practical proposals for such change as put forward by the Commission on the Status of People with Disabilities in its supplemental submission to the Constitution Review Group.

14.4 LEGISLATIVE ISSUES

14.4.1 INTRODUCTION

In this Section, the Task Force reviews legislation which has, or can have, particular relevance in relation to provision for an education service for persons with an ASD. The main purpose of the overview of legislation is to demonstrate the complexity and range of the issues involved and to make clear the need of

those involved in the provision of the education service for authoritative guidelines. Some of this legislation is educational legislation. Some relates to other areas and has provisions which may be applicable to the education service, such as legislation affecting rights, or complaints procedures available to citizens against the State.

14.4.2 THE CURRENT POSITION

Since 1980 a number of pieces of legislation have been enacted which taken collectively provide a statutory framework for the education service of persons with disabilities and special needs, including those with ASDs. In chronological order these are:

- i) Ombudsman's Act, 1980
- ii) Labour Services Act, 1987
- iii) Universities Act, 1997
- iv) Freedom of Information Act, 1997
- v) Employment Equality Act, 1998
- vi) Education Act, 1998
- vii) Qualifications (Education and Training) Act, 1999
- viii) National Disability Authority Act, 1999
- ix) Equal Status Act, 2000
- x) Education (Welfare) Act, 2000
- xi) Human Rights Commission Act, 2000
- xii) Teaching Council Act, 2001

The main provisions of these twelve Acts which deal with or otherwise affect educational provision for children with disabilities are outlined in Appendix 18. For more information please consult the full text of each Act. The main aim of the legislation appears to be to facilitate change, to prohibit discrimination, and to move towards equality. With regard to equality and the prohibition of discrimination against persons with disabilities, it is the view of the Task Force that there are weaknesses in the legislation.

For example, the Education Act 1998 represents a historic development in Irish education, providing for the first time since the establishment of the national school system in 1831 a comprehensive legal framework for education. Specific reference is made in the long title to provision for the education of persons with disabilities or special educational needs. The stated objectives of the Act include:

[to] give practical effect to the constitutional rights of children, including children who have a disability or other special educational needs” [Section 6(a)].

and to:

promote best practice in teaching methods with regard to the diverse needs of students and the development of the skills and competence of teachers [Section 6(f)].

The Education Act places responsibilities on the Minister in relation to the education of persons with special educational needs and responsibilities. In particular, it could be said to use the language of rights in placing responsibility on the Minister regarding such things as assessment, speech therapy and early and continuing education for those with special needs. The existing legal framework (constitutional, case and statute law) obliges the State/Minister to provide resources for primary education services and to do so for students with disabilities on an equalisation of opportunity basis.

However, from another perspective, it is the view of the Task Force that there is still some lack of clarity on the question of entitlements and rights for persons with ASDs and other disabilities. The Education Act requires the Minister to ensure that education suited to their needs is made available to persons with a disability resident in the State and, towards that end, to provide support services. There is, however, a lack of clarity regarding the provision of support services, e.g. speech and language therapy, in the least restrictive environment. No commitment is given within this provision to providing support services *in the least restrictive environment*. In Section 7 (4) (a) (1), the Act states that the Minister “*shall have regard to ... the resources available*”, subject to a number of checks and balances. The reference to “*resources available*” ensures that provision of support services remains in the realm of Ministerial discretion. The question of discretion vis-à-vis resources arises in relation to the provision of those educational facilities and services which are over and above constitutional entitlements. These entitlements must be responded to in full. As stated by Justice Barr, in *Sinnott v. the Minister for Education, Ireland and the Attorney General*:

A citizen's constitutional right must be responded to by the State in full. A partial response has no justification in law, even in difficult

financial circumstances which may entail raising of new tax revenue to meet such claims ... (p 27).

It is the view of the Task Force that the main shortcomings in the provisions in current legislation regarding resources are:

- i) the question of resources for the development of an administrative and professional structure commensurate with the requirements of implementing the legislative provisions is not addressed;
- ii) the distinction between the obligation on the state vis-à-vis funding to meet constitutional entitlements in relation to provision for education, and obligations regarding funding for education above and beyond constitutional entitlements is not addressed.

A further shortcoming in the legislation became evident through a number of submissions to the Task Force. This is the matter of exclusion or suspension of persons with an ASD from a school by virtue of reasons arising as a consequence of their disability, such as behaviours deemed 'inappropriate', 'hazardous' or 'challenging'. Provision is made in the Education Act for an appeal to the Secretary General of the Department of Education and Science where a school excludes, suspends or refuses to enrol a student or otherwise makes a decision which the Minister deems appeal-able. The Freedom of Information Act confers a right on parents to access information regarding their children held by public bodies such as the Department of Education and Science and the Health Boards, although this has not, as yet, been extended to schools. The Ombudsman investigates complaints from members of the public who feel they have been unfairly treated by public bodies, i.e. Government Departments or Health Boards.

The appeal mechanisms above would of necessity involve lengthy periods of time to bring to a conclusion. Childhood is short and time is not on the side of children with ASDs and other disabilities who may need speedy recourse to appeal and swift implementation of recommendations. The condition and educational gains of these children may deteriorate very quickly while they await the outcome of disputes between adults. The Task Force therefore recommends that no child or adult with an ASD should be excluded from a school or other service for any reason arising as a consequence of their disability. The Task Force also recommends the establishment of an accessible, independent, appeals procedure in which differences between parents and educational and service providers can be speedily resolved, without recourse to the courts. There are many models of good practice for such appeals systems internationally, especially in the United States. These should be reviewed and an accessible, independent, appeals system should be established without delay.

14.4.3 REVIEW OF CURRENT LEGAL PROVISION

14.4.3.1 Introduction

The legislative provisions outlined in the foregoing paragraphs, and those set out in more detail in Appendix 18, contain a wide range of statutory obligations regarding the education service which the State/Minister for Education and Science is required to discharge. In the course of his Supreme Court judgment in the Jamie Sinnott case, Mr. Justice Hardiman expressed the view that recent statutory provisions had effected a "revolution" in education legislation. He indicated that the provisions of the Education Act, 1998, together with the Equal Status Act, 2000 and the Education Welfare Act, 2000 imposed duties on public authorities which might be relevant to a person such as Mr. Sinnott or other disabled persons. Mr. Justice Geoghegan was of the opinion that it might well be the Minister for Education was at any rate now legally obliged to provide such services under the Education Act, 1998 (i.e., ongoing education into the future for Jamie Sinnott). As a basis for the provision of education for children with autistic spectrum disorders, however, it is the view of the Task Force that there are shortcomings in the current legislation, e.g.:

- many of the provisions are not sufficiently specific for implementation requirements;
- there is little provision for ensuring adequacy in delivery structures or for enforcement mechanisms;
- there are gaps in the provisions.

The Task Force, mindful of the outcome in the Sinnott appeal in the Supreme Court, takes as its key departure point in any debate about future reform the reality that Ireland has clear international legal obligations with respect to children and adults with disabilities in the context of education. In particular, it takes cognisance of the fact that Article 13 of the *International Convention on Economic, Social and Cultural Rights*, which deals with the right to education, conceives the underlying right to relate to basic learning needs for all persons including children and adults - something that is broader than, but encompasses, primary education.

It is also mindful of the range of arguments put forward by the Commission on the Status of People with Disabilities to the Constitutional Review Group (CRG) in 1995 for constitutional reform both on the equality and education provisions in the Constitution. Since not all these arguments were comprehensively or evenly dealt with by the CRG the Task Force feels that there is a good case to revisit the arguments for constitutional reform and that the outcome in the Sinnott appeal provides the occasion.

Lastly, and perhaps most importantly, the Task Force feels that the Supreme Court judgment places no obstacle whatever in the way of a modern civil rights statute for children and adults with basic learning needs. The Task Force feels the time has come to anchor bureaucratic prerogative with solid substantive and procedural rights. A good model to begin with would be the U.S. *Individuals with Disabilities Education Act*. The Task Force therefore recommends that a Disabilities Bill be drafted and enacted as a civil rights statute and that it contain an “Education (Special Needs)” section which will give practical effect to the rights of persons who have a disability or other special educational needs, including persons with autistic spectrum disorders, and to making provision for education and training based on the individual’s needs for as long as that person can benefit from such education and training.

14.4.3.2 Definitions of Disability

There are practically as many definitions of disability as there are agencies dealing with people with disabilities. Government departments generally define disability in the context of the services they deliver.

For example, the definitions of *disability* used in the *Equal Status Act 2000* and in the *Education Act 1998* are virtually identical, the only difference being that *total or partial absence* in the *Equal Status Act* becomes *total or partial loss* in the EA (see Appendix 18). The *Equal Status Act / Education Act* definition is derived from a definition developed for the *Disability Discrimination Act (Cth), 1992 (DDA)*, of the Commonwealth of Australia (Quinn, McDonagh and Kimber, 1993). The DDA definition in turn closely resembles that used in the *Equal Opportunity Act (Vic) 1984* of the State of Victoria, Australia, which had been formulated following a comprehensive consultation process. A requirement that the degree of impairment would be such as to substantially limit a major life activity of the person concerned was not included in the Australian DDA definition, as it was thought that its inclusion could be a source of unnecessary legal difficulties. By contrast, such a requirement is at the heart of the definition of disability used in the Irish *National Disability Authority Act 1999*.

The Education Act definition of disability requires further clarification for operational use, particularly with regard to inclusion/exclusion thresholds. In practice, the Department of Education and Science uses definitions of twelve disability categories, one of which relates to students with autistic spectrum disorders. The definition of autistic spectrum disorders, however, although comprehended in the *Education Act* general definition of disability, is not part of any legislation and does not have the force of law. However, as indicated above, the Department of Education and Science has operational definitions of autistic spectrum disorder, based on the diagnostic criteria, for operational and administrative purposes, see for example the copy of Circular 8/99 (Appendix 11)

on the Resource Teacher service for definitions of the different categories of disability.

14.4.3.3 The Right to Education

Under the terms of the *Education Act* (Section 7), children with disabilities are entitled to support services and a level and quality of education appropriate to meeting their needs and abilities. Support services include services such as psychological or speech and language therapy services or provision for education at a child's home that the Minister considers appropriate in the context of the *Education Act* requirements above. However, the *Education Act* makes little or no specific provision regarding many of the essential components required if a level and quality of education appropriate to meeting their needs and abilities is to be made available for children with autistic spectrum disorders, e.g.:

- i. making operational a process that identifies such children, determines their needs and abilities and provides an educational programme and support services appropriate to meeting their needs and abilities;
- ii. making operational a process that ensures that the education service for children with autistic spectrum disorders is provided, in the words of Mr. Justice O'Hanlon in the O'Donoghue case, "*in as full and positive a manner as is done for all other children in the community*".

As stated earlier, the *Education Act* as a whole may not provide for *enforceable rights* to education.

14.4.3.4 School Admission, Integration

Schools are required under the terms of the *Education Act* to publish their admissions policy, including that regarding admission to the school of children with disabilities. They are prohibited by the *Equal Status Act* from discriminating against children with a disability in relation to admission. Discrimination between children in relation to the way education is provided for them is a legal option only when safety is at issue, or when the continued viability of conditions for the delivery of the service on a group basis is at issue. Schools are to ensure that principles of equality and the right of parents to send their children to a school of their choice are respected in the general context of the effective and efficient use of resources and the rights of school patrons.

Under the terms of the *Education Act*, a refusal by a school to admit a student may be appealed by a parent to the Secretary General of the Department of Education and Science. Neither the *Equal Status Act* nor the *Education Act*, however, specifies enforcement mechanisms in respect of the above legislative provisions.

14.4.3.5 Discrimination

The provisions of the Equal Status Act entitle children with disabilities, including those with autistic spectrum disorders, to be treated by educational establishments as favourably as other children and also entitles them to a reasonable amount of positive discrimination to promote equality of opportunity. It is recognised in the Act, however, that considerations having significance for safety or service operability apply to all students, including those with disabilities.

The *Equal Status Act* allows preferential treatment that is *bona fide* intended to promote equality of opportunity for people who are unable to avail of the same opportunities as others. Educational institutions are obliged to do all that is reasonable to accommodate the needs of a person with a disability by providing special treatment or facilities in circumstances where without these, it would not be possible or would be unduly difficult for such a person to avail of the education service being provided.

Discrimination can occur if there is failure to do all that is reasonable, without incurring other than a nominal cost to the institution, with regard to facilities, arrangements, services or assistance to accommodate the needs of a person with a disability. In cases where more than a nominal cost is involved, there is an onus on the educational institution to apply to the Department of Education and Science or relevant state agency for grant assistance. A "*failure to provide its contractors with the resources necessary to meet the constitutional obligation of the State to educate the plaintiff and to meet his special needs*" was regarded by Justice Barr in the High Court in relation to the Sinnott case as a breach by the State of its obligations under the constitution.

However, the *Equal Status Act 2000* will not ensure that there are rights to equality in education services. The Act prohibits discrimination assuming that the individual can avoid a number of derogations and does not require a reasonable accommodation which would give rise to more than a nominal cost.

The *Education (Welfare) Act* requires that Boards of Management prepare a code of behaviour specifying the standards of behaviour to be observed by students [Section 23, 2]. No reference is made, however, to the need for positive discrimination with regard to students whose compliance capacity and disposition may be affected by a disability, e.g. children with autistic spectrum disorders.

14.4.3.6 Expulsion

The *Education Act* requires that the policy of a school in relation to expulsion be published. The *Education (Welfare) Act* applies only to students who are between six and eighteen years of age who have not completed three years of post-primary

education. Where school authorities believe such a student should be expelled, the *Education (Welfare) Act*:

- i) specifies a procedure to be followed which ensures continuity of an education service to the student,
- ii) prohibits the removal of the student's name from the school register until after the school has received notification confirming suitable alternative arrangements in respect of an education service for the student.

Under the terms of the *Education Act*, expulsion of a student may be appealed by a parent to the Secretary General of the Department of Education and Science. A number of cases involving suspension/expulsion of students with autistic spectrum disorders have been brought to the attention of the Task Force. Neither the *Education Act* nor the *Education (Welfare) Act* provide adequately for the protection of the rights of these children, while also having regard to the rights of other children.

14.4.3.7 Further and Continuing Education

The objects of the *Qualifications (Education and Training) Act 1999* (QETA) include the promotion of lifelong learning for all learners, including learners with special educational and training needs, and the promotion of diversity in further education and training. All those involved in its implementation are required, in exercising their functions, to have regard to the objects of the Act. There is a danger in this arrangement that what is everybody's business in effect becomes nobody's business. In England responsibility for the provision of further education for those with special needs is included among the duties of the funding agency (Further Education and Funding Council, 1996). *The Further and Higher Education Act, 1992* (FHEA) requires that the Further Education and Funding Council "shall have regard to the requirements of persons having learning difficulties" in the course of carrying out its general duties to provide full-time and part-time further education.

14.4.3.8 Resources

From one perspective, it could be argued that the Minister for Education and Science has no legal discretion with regard to provision of resources to meet constitutional obligations. Ministerial discretion concerning resources generally is required to have regard to:

- i) the fundamental obligation on the State to meet constitutional requirements regarding a certain minimum education for all children, including those with disabilities,
- ii) policy regarding those elements of the education service that are above and beyond constitutional imperatives,
- iii) overall exchequer resources and the proportion of these that are allocated to fund the education service.

The obligation on the State and the Minister has been clarified in:

- a) case-law judgements, specifically those clarifying the right of children with disabilities to a suitable equally effective primary education; e.g. *Paul O'Donoghue v. the Minister for Education and others*, *Jamie Sinnott v. the Minister for Education and others*
- b) the provisions of statute law, e.g.:
 - the *Education Act, 1998* - It shall be a function of the Minister under the Act "*to ensure ... that there is made available to ... a person with a disability... support services and a level and quality of education appropriate to meeting the needs and abilities of that person*" [Section 7]. The Minister is required to do this "*as far as practicable and having regard to the resources available*" [Section 6 (b)].
 - the *Education (Welfare) Act, 2000* - "*an Act to provide for the entitlement of every child (generally aged six-sixteen years) in the State to a certain minimum education ...*"
 - the *Equal Status Act, 2000* - the Act prohibits discrimination, that is treating one person less favourably than another on one of the discriminatory grounds, e.g. disability [Section 3 (1)].

The existing legal framework (constitutional, case and statute law) obliges the State/Minister to provide resources for primary education services and to do so for students with disabilities on an equalisation of opportunity basis. Nevertheless, as pointed out in Section 14.4.2 above, there is still some lack of clarity on the question of entitlements and rights.

There are, however, no provisions in the legislation with regard to arrangements for appealing the outcome of an assessment or of a determination of special educational need. The Task Force therefore recommends the establishment of an

accessible, independent, appeals procedure in which differences between parents and educational and service providers can be speedily resolved, without recourse to the courts. There are many models of good practice for such appeals systems internationally and such an appeals system should be established without delay.

14.4.3.9 The Disabilities (Education and Training) Bill

This Bill is to be published during the period covered by the Programme for Prosperity and Fairness (PPF). It is to co-ordinate special education facilities across government departments, to improve and extend special provision and to guarantee its delivery.

In its reference to the proposed Disabilities Bill, the *National Children's Strategy: Our Children - Their Lives* states that:

A Disabilities Bill which will provide for specific measures to advance and underpin the participation of people with disabilities in society, including the participation of children with disabilities, is being prepared and is expected to be published in 2001.

The National Disability Authority (NDA) has made the following submission for consideration in the drafting of the Disabilities Bill:

The legislation should contain among other things the following:

- *The right to an equally effective education;*
- *A statutory presumption in favour of mainstream;*
- *An enumeration of the narrow grounds for excluding children with disabilities;*
- *Annual individualised education plans leading to a “contract” between school, child and parent;*
- *Statement of resources dedicated to this end and in place before term begins;*
- *Tailored curricula;*
- *Rights to related services;*
- *Complaints mechanism.*

14.5 THE NEED FOR LEGISLATIVE REFORM

14.5.1 Civil Rights Statute on the Educational Rights of Persons with Disabilities

In view of the lack of certainty as to rights and entitlements for persons with autistic spectrum disorders and other disabilities, outlined above, the Task Force

recommends that a civil rights statute dealing with the educational rights of persons with disabilities should be enacted. This statute should set out substantive and procedural rights. The Task Force considers that the practical proposals for such a civil rights statute made by the National Disability Authority should inform the content of such a statute. Such statute should be clearly premised on the philosophy of a right to an equally effective education. Among other things the statute should contain

- a clear and strong statutory presumption in favour of the mainstream,
- a statutory guarantee that no person with an ASD should be excluded from a school or other service for any reason arising as a consequence of his/her disability,
- a statutory statement of need in respect of each individual,
- a process whereby an annual *Individual Education Plan* could be identified and a 'contract' signed *well before* each school year involving the parents, the school, the child and other relevant independent professionals,
- a statement of resources to be dedicated to this end (dedicated and put in place *well before* the commencement of the school year),
- a genuinely tailored curriculum with a prior statement of testing modalities that makes sense for the person,
- a statutory right to related professional and other services to enable the person take advantage of his/her educational opportunities,
- a statutory right to appropriate on-going education and training, according to need, for adults with disabilities (including ASDs),
- a method of evaluation of progress,
- a statutory right to be placed in a school that is reasonably proximate in geographic terms,
- an independent appeals/complaints mechanism in which differences between parents and educational and service providers can be speedily resolved without recourse to the courts.

The Task Force recommends that the title of the statute should clearly reflect the movement to a civil rights-based philosophy and should therefore be entitled *Individuals with Disabilities Education Act -Ireland* (IDEA-I). In addition to providing for substantive and procedural rights such a statute should establish an independent monitoring body for the civil rights of persons with disabilities in education.

14.5.2 Legislating for Affirmative Action - Education Provision in the Disabilities (Education and Training) Bill

The Task Force recommends that the proposed Disabilities Bill, recommended by the National Disability Authority, the National Children's Strategy and signaled by the Minister for Education and Science in statements to the media in July 2001, should make legal provision for the kinds of positive action that will

be required to make the educational rights of persons with disabilities a reality. The education section of the Disabilities Bill could be incorporated into the primary civil rights statute or it could stand alone. Either way it should be seen as complementing the civil rights of persons with disabilities to education.

14.4.3.10 Services Through the Medium of Irish

The Task Force believes that assessment, education and support services should be available through the medium of Irish to persons with an ASD whose first or family language is Irish.

The Education Act 1998 provides that it shall be a function of the Minister to ensure that support services and an education appropriate to their needs and abilities is available to persons with disabilities (7) (1) (a) and that support services to schools which teach through Irish, or which request such provision, shall be provided through Irish (7) (2) (d). The EA 1998 also provides that the Minister shall establish a body of persons to advise the Minister on policies and the National Council for Curriculum and Assessment (NCCA) on matters relating to the provision of education through Irish, to provide support services through Irish and to conduct research (31) (1).

The right of persons with an ASD whose first or family language is Irish, to access to assessment, education and support services through the medium of Irish is not, however, addressed in the EA 1998 with sufficient specificity. The Task Force is of the opinion that specific provision should be made in respect of this right in the forthcoming *Official Languages Equality Bill (An Bille Comhionannais um Theangacha Oifigiúla)*. The general scheme of this *Bill* has been approved by government (Press Release, 12.6.01, Department of the Arts, Heritage, Gaeltacht and the Islands). It is intended that it will specify the obligations on the state in relation to the provision of services for citizens in the official languages.

14.5.3 Administrative Reform

The Task Force considers that administrative reform is also required. It endorses the establishment of a new National Council for Special Education, and the establishment of Regional Co-ordinators for Special Education (in the Department of Education and Science's *Report of the Planning Group: A National Support Service for Special Education for Students with Disabilities* (2000) they are referred to as Special Needs Officers), as included in proposals to Cabinet presented by the Minister for Education and Science (*Irish Times*, 2nd August 2001). The Task Force endorses the need for a new appeals structure for parents of children with special needs who are unhappy with the education provision given to their child (*ibid.*), but asserts that such an appeals structure must be independent. The Task Force also endorses the need for a detailed

programme for each child with special needs to be worked out by experts in the area (ibid.).

The Task force also recommends that, under the proposed *IDEA-I*, a Disabilities Civil Rights Section should be established within the Department of Education with overall responsibility for policy formulation in relation to educational rights for people with disabilities. The Task Force recommends that Regional Resource Centres be established under the *IDEA-I*, in the offices of the Special Needs Officers, to equip parents with the means by which they can make the best use of the system of rights provided for by the Act.

The Task Force recommends that, since knowledge is power, the Department of Education and Science should prepare and update regularly a user-friendly guideline handbook regarding the responsibilities, procedures and practices involved in the provision of the right to suitable education for persons with disabilities, including those with autistic spectrum disorders, and dealing also with the implementation of the legislative provisions outlined above.

14.6 Recommendations

The Task force recommends:

1. that urgent attention be paid by the Government to the need for appropriate constitutional reform to provide clearer provision for the rights of persons with disabilities to education and to provide a more solid legal basis for advanced legislation in the field; that the constitutional right to education be viewed against the over-arching right to equality; that the right to equality be considerably strengthened; that the constitutional right to education be reformulated to concentrate more on the substantive right itself; that the main emphasis in any reformulated right be the right to an *equally effective* education for all, regardless of difference; that the basic right at stake be 'basic learning' for all, which includes adults;
2. that a civil rights statute dealing with the educational rights of persons with disabilities be enacted; that this statute set out substantive and procedural rights; that the practical proposals for such a civil rights statute made by the National Disability Authority inform the content of such a statute; that this statute be clearly premised on the philosophy of a right to an equally effective education; that among other things the statute contain
 - a clear and strong statutory presumption in favour of the mainstream,
 - a statutory guarantee that no person with an ASD should be excluded from a school or other service for any reason arising as a consequence of his/her disability,

- a statutory statement of need in respect of each individual,
 - a process whereby an annual *Individual Education Plan* could be identified and a 'contract' signed *well before* each school year involving the parents, the school, the child and other relevant independent professionals,
 - a statement of resources to be dedicated to this end (dedicated and put in place *well before* the commencement of the school year),
 - a genuinely tailored curriculum with a prior statement of testing modalities that makes sense for the person,
 - a statutory right to related professional and other services to enable the person take advantage of his/her educational opportunities,
 - a statutory right to appropriate on-going education and training, according to need, for adults with disabilities (including ASDs),
 - a method of evaluation of progress,
 - a statutory right to a place in a school that is reasonably proximate in geographic terms
 - an independent appeals/complaints mechanism in which differences between parents and educational and service providers can be speedily resolved without recourse to the courts;
3. that the title of the statute clearly reflect the movement to a civil rights-based philosophy and should therefore be entitled *Individuals with Disabilities Education Act -Ireland (IDEA-I)*; that, in addition to providing for substantive and procedural rights such a statute establish an independent monitoring body for the civil rights of persons with disabilities in education; that, under the proposed *IDEA-I*, a Disabilities Civil Rights Section be established within the Department of Education with overall responsibility for policy formulation in relation to educational rights for people with disabilities; that Regional Resource Centres be established under the *IDEA-I* to equip parents with the means by which they can make the best use of the system of rights provided for by the Act;
 4. that the proposed Disabilities (Education and Training) Bill make legal provision for the kinds of positive action that will be required to make the educational rights of persons with disabilities a reality; that the education section of the Disabilities Bill either be incorporated into the primary civil rights statute or that it stand alone - either way that it complement the civil rights of persons with disabilities to education;
 5. that assessment, education and support services be available through the medium of Irish to persons with an ASD whose first or family language is Irish (e.g. pupils enrolled in Scoileanna Lán-Ghaeilge);
 6. that specific provision be made in the forthcoming *Official Languages Equality Bill* in respect of the right of persons with an ASD whose first or family language is Irish, to have access to assessment, education and support services through the medium of Irish;

7. that the Department of Education and Science prepare and update regularly a user-friendly guideline handbook regarding the responsibilities, procedures and practices involved in the provision of the right to suitable education for persons with disabilities, including those with autistic spectrum disorders, and dealing also with the implementation of the legislative provisions outlined above.

CHAPTER 15

POLICY

15.0 POLICY DEVELOPMENT AND SPECIAL NEEDS EDUCATION FOR CHILDREN WITH DISABILITIES

This chapter deals with policy developments under three broad headings - "*Current Position*", "*Review of the Current Position*" and "*Recommendations*". Following a brief reference to the historical development of special needs education in Ireland, the section on "*Current Position*" gives a short description of the various reports, including the 1995 White Paper, which since the 1960s have formed part of the policy development process. Current policy initiatives are outlined - the many elements of policy that have been incorporated into statute law have already been dealt with in Chapter 4. Constitutional obligations to which the state is required to have regard when framing educational policy for children with disabilities, such as children with an ASD, are outlined in Chapter 3. Policy shortcomings are identified in "*Review of the Current Position*" and proposals to address them are put forward in "*Recommendations*".

15.1 THE CURRENT POSITION

15.1.1 Historical Background

15.1.1.1 Beginnings of Special Education Provision in Ireland

The first special educational services were set up to cater for students with hearing impairment and those with visual impairment. From the middle of the nineteenth century a number of religious orders were active in this field. Services for students with general learning disabilities and physical disabilities were developed much later. As late as 1950 only one special school for students with general learning disabilities had been given official recognition.

15.1.1.2 Expansion from the 1960s

The *Report of the Commission of Inquiry on Mental Handicap (1965)* provided recommendations regarding diagnosis, educational placement, training and care of children and adolescents with a general learning disability (mental handicap). Special educational provision for students with a general learning disability was subsequently expanded. This was done mainly within the national school system

through establishing special national schools and special classes in mainstream national schools.

By the 1980s many parents of children with moderate general learning disability wished to have suitable education provided for their children with their peers in ordinary schools, at primary and post-primary levels. A number of special classes for such students were subsequently established in mainstream national schools. There are, however, few such special classes in post-primary schools. More recently special classes for students with other disabilities, e.g. specific speech and language disorders, autistic spectrum disorders, Asperger's Syndrome and specific learning disability or dyslexia, were established.

15.1.2 Recognition of right to Special Needs Support

A major breakthrough in special provision was achieved with the Government decision of October 1998, which recognised that all students with disabilities within the mainstream national schools system have a right to automatic provision to meet their needs. Since then the Department of Education and Science provides supports, in the form of additional teaching and special needs assistant services, for students with disabilities attending mainstream national schools. Circulars 8/99 and 9/99 set out the procedures to be used by national schools in applying for additional support in respect of pupils with disabilities and special needs. "Autistic Spectrum Disorders" are listed as a separate disability category in these Circulars and are defined as follows:

A suitably qualified professional will have assessed and classified such students as having autism or autistic spectrum disorder according to DSM-IV or ICD-10 criteria.

15.1.3 Provision for Post-Primary Students

Until the early nineties the great majority of students with disabilities in the post-primary age range attended special national schools. These schools may enrol students in the age range four-eighteen years. As the number of students with disabilities attending mainstream post-primary schools increased, special provision was made for them on an ad hoc basis. Resources were provided by the relevant sections of the Department in response to demand. The range of provision has included special classes, resource teacher posts, individual one-to-one tuition and special needs assistants.

15.1.4 Policy Influences since the 1960s

A number of Government and other reports on educational provision or affecting educational provision for students in various categories of disability have been published since the *Commission of Inquiry on Mental Handicap* reported in 1965. An outline of the main provisions of these is provided in the following paragraphs 15.1.4.1 to 15.1.4.15. An outline of the provisions of other reports having less direct relevance to educational provision for persons with autistic spectrum disorders is given in Appendix 19.

15.1.4.1 The Primary School Curriculum: Teacher's Handbook, Parts I, II (1971)

The need to take due account of the full range of individual differences in pupils was adopted as a basic principle in the 1971 Primary School Curriculum. It stated that:

each child ... deserves to be ... provided with the kind and variety of opportunities ... which will enable him to develop his natural powers at his own rate to his fullest capacity (Primary School Curriculum, Teacher's Handbook, Part 1, p 13).

15.1.4.2 The Education and Training of Severely and Profoundly Mentally Handicapped Children in Ireland (1983)

The main recommendation of this Report was that children with severe and profound general learning disabilities should have access to teachers paid and supervised by the Department of Education and Science. The delay in implementing this recommendation led to the parents of some children looking to the courts for vindication of their rights to a special education service.

15.1.4.3 Report of the Special Education Review Committee (SERC) (1993)

The most recent major Government Report on special education provision was the *Report of the Special Education Review Committee*. This was the first review dealing with all the disability categories for which special education provision was made and, together with the Education Act (1998) and case-law, is an important basis for present policy. Its publication gave a new impetus to special needs issues. The recommendations brought forward in the SERC Report called for improved levels of provision across the spectrum of special needs and attached particular importance to the need to support students with disabilities in integrated settings.

There is a short section in the SERC Report under the heading "Pupils with Childhood Autism". This was regarded as equivalent to "autistic disorder" in the DSM-IV diagnostic system. The SERC Report did not deal specifically with other pervasive developmental disorders such as Asperger's Syndrome. It regarded identification and intervention early during the pre-school period as a first priority for children with autism. It saw autism *"as one of the most severe developmental disorders affecting children"* and considered that it would *"be necessary to take account of factors such as the pervasiveness and degree of severity of the autistic symptoms and the level of intelligence and of language development when considering the question of the most suitable school enrolment in individual cases"*. In paraphrase, the recommendations in respect of educational provision for children with autism included the following:

- in special schools (other than those for pupils with emotional and behavioural disorders), a teacher post should be sanctioned in respect of each six pupils with autism;
- additional teaching support (minimum five hours per week in respect of each pupil) should be provided for pupils with autism who are enrolled in ordinary schools;
- a classification system such as DSM-IV or ICD-10 should be used in ... referrals of children with autism for enrolment in schools;
- Special Needs Assistants (on the basis of one per class group) should be appointed to schools and classes having pupils with autism.

15.1.4.4 Services for Persons with Autism, Department of Health, 1994

This Report addresses the needs of children who "manifested autism to a marked degree". It does not include those with AS/HFA.

Three general principles which should underpin the treatment of persons with autism are put forward:

- Where possible the child should be treated and educated in the same setting as all other children, i.e. in mainstream services.
- Where mainstreaming is not possible, specialised services should be provided.
- *... those involved in the child's ... education should have an awareness of the special nature of autism and should have the training to deal with the special demands it presents.*

The following are among the recommendations made:

- *Regional diagnostic clinics should be established to provide a third-level diagnostic team and to act as a resource centre providing teaching programmes for staff in a variety of disciplines.*
- *a range of school placement options is required depending on the needs of the individual child, the level of his/her mental handicap and taking geographical considerations into account.*
- *Health boards should establish a separate database on persons with autism in their area.*

15.1.4.5 Charting our Education Future – White Paper on Education (1995)

The *White Paper on Education (1995)* was published following a lengthy consultation process that included the publication of a *Green Paper* and the *Report of the National Forum on Education*. In relation to provision for students with disabilities at first and second levels, the White Paper stated that a special task force had been set up within the Department to implement, as resources would permit, the recommendations of the SERC Report. A number of the policy statements were made regarding participation by students with disabilities in higher education e.g.:

A major objective of the Government is to promote equality of access to higher education, irrespective of social class, age or disability, for all who have the capacity to benefit from it; and

Third-level institutions will be encouraged to provide special arrangements for students with disabilities. The Higher Education Authority will pursue a supportive and monitoring role and will actively encourage the development of such special arrangements in all institutions.

In relation to its general operation, the White Paper stated that the Department of Education had been unable to give due attention to policy analysis, policy development, strategic planning and evaluation of outcomes, which should have been its main concerns.

15.1.4.6 Report of the Commission on the Status of People with Disabilities (1996)

The *Commission on the Status of People with Disabilities* was established in 1993 to advise the government on the practical measures necessary to ensure that people with disabilities could exercise their rights to participate, to the

fullest extent of their potential, in economic, social and cultural life. *The Report of the Commission on the Status of People with Disabilities* contains 402 recommendations involving legislative solutions, proposals for new policy initiatives and new structures for the delivery of quality services.

15.1.4.7 Strategy Statement -Implementation of the Public Service Management Act, 1997

This Report was published by the Department of Education and Science in 1998. The mission statement of the Department given in the Report is:

to ensure the provision of a comprehensive, cost-effective and accessible education system of the highest quality, as measured by international standards, which will:

enable individuals to develop to their full potential as persons and to participate fully as citizens in society; and

contribute to Ireland's social and economic development.

The main challenges facing the Department for the future were identified. These included:

the challenge of contributing to the goal of an inclusive society, where all citizens have the opportunity and the incentive to participate fully in the social and economic life of the country,

the challenge of meeting the particular and diverse needs of specific groups in society, including those with special educational needs ...

the challenge of securing the necessary human and financial resources to ensure that the Department's objectives and goals can be achieved with professionalism, efficiency and cost-effectiveness.

On the key question of the ability of the Department to meet its challenges the report states:

Achievement of the Department's goals, objectives and outputs is critically dependent on a level of financial and human resources commensurate with the complexity and scale of the tasks involved. There has been a significant and continuing expansion in the range of activities, programmes and services provided by the Department that has not been matched by a corresponding growth in staff numbers. In this regard, the adequacy of the existing level of human resources to achieve the outputs specified in this document

is the subject of ongoing discussions with the Department of Finance.

15.1.4.8 Building a Future Together (1998)

This Report was published by the Department of Justice, Equality and Law Reform and approved by the Government in July 1998. In the overall context of mainstreaming services for people with disabilities, it recommended that the National Rehabilitation Board (NRB) be dissolved and that its staff and functions be transferred to other agencies. This was implemented in June 2000 as follows:

Responsibility for vocational training and employment services were transferred from the Department of Health and Children to the Department of Enterprise, Trade and Employment, i.e. Occupational Guidance, Employment Supports, Positive to Disability Initiative and Supports to Vocational Training were transferred to FÁS,

Information, Advice and Advocacy, National Disability Resource Centre and Access Officer Service were transferred to COMHAIRLE,

Hearing Service/Audiology was transferred to the Health Boards,

Day activation and rehabilitative workshops continued to be the responsibility of the Department of Health and Children. Supports to Rehabilitation Training were transferred to the Northern Regional Health Authority (on an interim basis to allow for full integration into Regional Health Boards within a two year period),

Life-skills training for people in health funded day care programmes continued to be the responsibility of the Department of Health and Children as part of the training continuum,

The NRB advisory role reverted to the Department of Health and Children, and Library Services were transferred to the National Disability Authority, and

Psychology Services were transferred to the National Educational Psychology Service (NEPS).

15.1.4.9 Primary School Curriculum (1999)

In general terms, the aims of primary education for pupils with special educational needs are as stated for all pupils in the *Introduction to the Primary School Curriculum (PSC) 1999*:

to enable the child to live a full life as a child and to realise his /her potential as a unique individual (p 7);

and also

to enhance the quality of children's learning and to provide them with a developmental experience that is relevant to their present and future needs (p 75).

For pupils with special educational needs, the PSC states that it is crucially important that they “*have available to them a level and quality of education appropriate to their individual needs and abilities*”. While the PSC presents summaries of “*the skills and concepts to be developed at the different class levels*”, it refers also to the need to make due allowance for individual differences as a “*learning principle*” (p 8). It outlines “*a detailed and structured framework of content*”(p 6), “*affords flexibility to the school and the teacher in planning the learning experiences that are useful to the individual child*”(p 10), offers choices in the selection and sequencing of content and assumes that schools “*will adapt and interpret the curriculum as necessary to meet their own unique requirements*”(p11). The “*Teacher Guidelines*” offer advice on curriculum, organisation and classroom planning for each subject area. The Principal and staff are to “*identify educational goals that are both relevant and realistic and that will reflect the needs, aptitudes and circumstances of the pupils ...(p19)*”. In doing this, schools are to have regard to:

the child's stage of development;

differences between children owing to variations in personality and intellectual and physical ability;

the particular circumstances of the school (p 37).

The teacher “*will take account of the differences in children, their interests and motivation, their varied personalities, and the many ways in which they learn*”. She/he will “*interpret the needs of the child and the requirements of the curriculum in order to provide effective learning experiences*”. Classroom planning “*is based on curriculum content, on the school plan for that particular subject, and on the need to respond to the particular needs, aptitudes and interests of the children*”. In general, “*the teacher exercises professional discretion in planning and directing the learning process*”.

15.1.4.10 National Council for Curriculum and Assessment (NCCA)

The NCCA advises the Minister regarding curriculum and syllabuses for students with disabilities. It has begun the process of developing curricula for students with special educational needs and proposes to focus initially on curriculum provision for students with general learning disabilities (mild,

moderate, severe and profound). An introductory report "*Special Educational Needs: Curriculum Issues*" was published in 1999.

15.1.4.11 White Paper on Adult Education

The Minister of State for Adult Education at the Department of Education and Science, Mr. Willie O’Dea, T.D., on 2.8.00 launched a White Paper called “*Learning for Life*” on the future development of Adult Education. To cater for people with disabilities, the White Paper proposes several measures, ranging from disability awareness training to specific initiatives for literacy for the deaf. The Paper proposes that the existing Disability Fund under which additional supports (such as adaptive equipment, transport, interpreters, readers, transport, etc.) are provided to PLC or third-level students, should be extended to other spheres of adult education.

15.1.4.12 Department of Education and Science - Review of Department's Operations, Systems and Staffing Needs, 2000 (The Cromien Report)

The Minister for Education and Science commissioned Sean Cromien, a former secretary of the Department of Finance, to conduct a review of the Department's operations, systems and staffing needs. It had become clear to the Minister that "my Department faced serious operational, systems and staffing difficulties in delivering quality services in a highly challenging environment" (Press Release 20.6.01). In a report regarding the review in the Irish Times of 11th May 2000, Sean Flynn, Education Editor, spoke of "increasing concern in the Department about its volume of work". He went on to state that:

In recent years, the Department of Education has found it more difficult to focus on such functions as policy analysis and strategic planning because of its administrative workload;

... it is modestly staffed compared to many other Departments, with around 900 staff - compared, for example, to about 4,000 in the Department of Agriculture.

The "Cromien Report" recommended a number of structural reforms of the Department of Education and Science including the establishment of a "National Council for Special Education" with responsibility for a wide range of special education services. It has also recommended the establishment of a network of local area-based offices.

15.1.4.13 Report of the Working Group on Asperger's Syndrome, 2001

This "*Review of the Needs and Services for Children and Young People with Asperger's Syndrome*" in the Area Health Boards of the Eastern Region (South Western, East Coast and Northern) was carried out as part of the service plan for the Boards' child and adolescent psychiatric services.

The Working Group agreed that, in addition to children with Asperger's Syndrome, for the purpose of the review "children and young people who had been diagnosed as being High Functioning Autistic with an IQ of seventy or over" would also be included. The term AS/HFA would be used to refer to the wider group. The Working Group was of the opinion that "the importance of education for the development of the individual's potential cannot be overestimated and keeping the child with AS/HFA at school for as long as possible should be the main focus of professional interventions".

A survey "Regarding services for People with Asperger's Syndrome" was carried out by ASPIRE during August 2000. The survey found thirty-seven children with "a diagnosis of Asperger's Syndrome" (including four with "Asperger's Syndrome plus other disorder") under eighteen years of age in counties Dublin, Kildare and Wicklow - the Eastern Regional Health Authority area. The survey reported that fifteen children with Asperger's Syndrome were in "mainstream school without support". It is not clear, however, whether all of the fifteen had a diagnosis of Asperger's Syndrome.

A limited survey was undertaken to ascertain the prevalence of AS/HFA (IQ above seventy) and service provision for children/adolescents under eighteen years of age in the Eastern Regional Health Authority. A total of eleven completed questionnaires were received from twenty psychiatrists. The survey reported that the ICD 10, DSM IV and Gillberg & Gillberg's 1989 criteria for diagnosis of Asperger's Syndrome were widely used. It was generally agreed by psychiatrists that ambiguities in diagnoses did arise even using these methods. Issues highlighted in this survey included:

All psychiatrists referred to the need for appropriate school placements for children- preferably in mainstream school-with support if necessary. If a child cannot be maintained in mainstream school, then special classes in mainstream schools should be the choice...;

The fundamental importance of education for children and the need to deal with the real danger of isolation and bullying, which so often forces children out of school;

Teenagers were mentioned many times as being in particular need of help with emotional problems such as depression or anxiety...

The Working Group, inter alia, recommended:

in relation to diagnosis that:

The appropriate professionals should come together to agree a common diagnostic formula for AS/HFA for the purpose of diagnosing the condition as early as possible. (p.39)

in relation to education that:

... every possible effort should be made to keep children in an appropriate school placement as long as necessary;

Teachers need to be aware of and have an understanding of AS/HFA;

Modules on the education of children with AS/HFA should be included in ... teacher training courses;

better liaison should be developed between the teachers and the relevant health professionals;

... all intervention programmes ... be critically evaluated. (pp.42-43)

15.1.4.14 Report of the Action Group on Access to Third Level Education, 2001

The Action Group was set up by the Minister for Education and Science, Dr. Michael Woods, T.D. in September 2000 in fulfillment of a commitment in the Programme for Prosperity and Fairness. It was to advise him on the most effective ways to increase participation by disadvantaged groups (students with disabilities, students from disadvantaged backgrounds and mature “second chance” students) at third level.

The Group’s report sets out a comprehensive framework for increasing participation by such students and contains seventy-seven recommendations. The recommendations most directly relevant for students with disabilities are the following:

by 2006, the proportion of undergraduate students with disabilities in full-time third-level courses should have increased to 1.8 per cent;

Each university and institute of technology should have, in addition to an Access Officer, at least one Disability Officer;

A National Office with a dedicated staff should be set up within three months to oversee a national programme to improve access to higher education. When established, the National Office should also be responsible for allocating funding for initiatives to promote equity in access including the existing Special Fund for Students with Disabilities and the Student Assistance/Access Fund which is included in the National Development Plan.

In launching the report (DES Press Release 9.7.01) the Minister said that, “the special fund for students with disabilities should be converted into a needs-based scheme in line with the action taken by the Government at primary and second level”. The Minister also said that his Department would now prepare an Action Plan to urgently advance the proposals of the Action Group.

15.1.4.15 Current and future supply and demand conditions on the labour market for certain professional therapists, 2001 - the Bacon Report

This report concludes that a major expansion is essential in the numbers of therapy professionals over the next fifteen years. The Report recommends:

a doubling in the number of physiotherapists;
an increase of over 150% in the number of occupational therapists; and
a fourfold increase in the number of speech and language therapists.

This will require a significant increase in training places with a recommended annual increase from 25 to 75 course places for speech and language therapy, from 35 to 75 course places for occupational therapy and from 120 to 145 course places for physiotherapy. Other key recommendations of the report relate to:

provision of sufficient clinical placements within the Health Service through the establishment of a national network of Clinical Placement Co-ordinators;
need for fast-track qualification and review of the existing training system;
concerted recruitment from overseas;
estimation and projection of Healthcare demand as a basis for human resource planning in the Health Service.

An Inter Agency Group, comprising representative of the Department of Health and Children, the Department of Education and Science and the Higher Education Authority has been created to ensure the provision of the additional places as an urgent priority.

15.1.5 Current Initiatives

15.1.5.1 The National Agreement “Programme for Prosperity and Fairness” (2000)

A Disabilities Bill is to be published during the period of the programme. It will provide a legislative basis to advance and underpin participation by people with disabilities in society. Initial preparatory work has commenced in the Department of Justice, Equality and Law Reform on identifying issues for inclusion in the Bill. The Commission on the Status of People with Disabilities has identified education and the provision of educational opportunities for students with disabilities as issues that it would like to be covered in a Disabilities Bill.

The Department of Justice, Equality and Law Reform are to put arrangements in place during the period of the programme to review and identify key statistical needs in relation to people with disabilities or categories of people with disabilities for the purpose of informing policy, planning and the delivery of services.

15.1.5.2 Database of Students with Special Educational Needs

In April 2000, the Minister announced plans for the development of a database to provide critical information in respect of all students, including those with special needs, attending mainstream schools. A total of £4.5 million is being provided to develop the database over the next three years. It is intended to implement the first phase of the plan in a pilot group of schools during the school year 2001/2002. (It is noted that the Department of Health and Children has for a number of years been operating a National Intellectual Disability Database and that a National Database Development Committee was established in 1998 to draw up plans for the development of a national database on the health service needs of people with physical and sensory disabilities.)

15.1.5.3 Early Childhood Education Measures

A total of £74 million has been provided for the implementation of the proposals in *Ready to Learn – White Paper on Early Childhood Education* (1999). The White Paper focuses on increasing participation among priority groups, in particular children who are educationally disadvantaged and children with disabilities.

15.1.5.4 Developments in relation to Autism (autistic spectrum disorders)

On 11.10.2000 the Minister announced a number of improvements to the education service for "*children with autism*". A Press Release lists these as follows:

- the introduction of a nation-wide pre-school education service for children with autism;
- the extension of the school year through July in the case of all special facilities catering for children with autism;
- an increase from one to two special needs assistants in respect of each special class catering for children with autism;
- a programme of specialist training for teachers of children with autism; and
- the establishment of an inter-Departmental team of high-level officials to co-ordinate response to the needs of children with autism.

Plans were announced also to appoint an internationally recognised expert in the field of autism to advise the Department on the development of services and a clinical psychologist to advise on the needs of individual children with autism.

15.1.5.7 The National Educational Psychological Service (NEPS)

A Planning Group representative of all the partners in education reported in September 1998 that the situation with regard to access to psychological support services was inadequate in many areas of the country. The Group recommended that the Department of Education & Science establish a National Educational Psychological Services Agency (NEPS) as an executive agency which would be operationally separate from the other divisions and sections of the Department. NEPS was formally established in September 1999.

The Minister for Education and Science, Dr. Michael Woods, T.D., on 28.5.01 announced that funding of £1.25m is being made available in the current year to purchase assessment services from suitably qualified private practitioners pending the recruitment of the full complement of psychologists to NEPS. At present NEPS employs eighty-two psychologists, increasing by June 2001 to one hundred. A further twenty-eight psychologists are to be recruited before the end of 2001 and recruitment will continue until the target of 200 psychologists is reached

A press release on 1.7.01 gave further details of the initiative. Primary schools not yet having access to the service provided by the National Educational

Psychological Service (NEPS) will be able to commission psychological assessments from private practitioners NEPS will also commission assessments on behalf of primary and post-primary schools with access to its service but where there is a backlog of urgent referrals for special educational needs. Before the September 2001, an information pack containing detailed guidelines on the new service is to be sent to all schools The information pack will, *inter alia*, include a list of appropriately qualified psychologists and guidance on how to involve parents fully in the assessment of their children.

15.1.5.8 National Development Plan (NDP)

The Minister for Education and Science informed the Dáil on 8.6.2000 that the National Development Plan, 2000-2006, provides for a Third Level Access fund totalling £95m. to promote participation of students with disabilities, students from disadvantaged backgrounds and mature “second chance” students. It will, *inter alia be used to:*

- Meet the specific needs of students with disabilities in terms of equipment and support services;
- Develop outreach initiatives currently undertaken by a number of third-level institutions which involve links with second level schools and community groups and are designed to both assist students to meet the points requirements for the standard CAO entry procedures and to provide complementary special entry arrangements; and
- Expand the provision of particular services, such as counselling and mentoring services, to meet the needs of non-traditional students.

The NDP also includes provision of £175m for vocational Training and Pathways to Employment for people with disabilities.

15.1.6 Policy vis-a-vis Inclusive Education

In a resolution of the EU Council of Ministers during the Irish Presidency in 1990, member states committed themselves:

to intensify, where necessary, their efforts to integrate or encourage integration of pupils and students with disabilities, in all appropriate cases, into the ordinary education system, within the framework of their respective education policies and taking due account of their respective education systems.

For a number of years it has been the policy of the Department of Education and Science that, except where the degree of special need of the individual child

renders this impracticable, appropriate education for children with disabilities, including those with an autistic spectrum disorder, be made available in ordinary schools. All students with disabilities in mainstream classes in national schools, including those with autistic spectrum disorders such as Asperger's Syndrome or High Functioning Autism, are since 1998 recognised as entitled as of right to support to assist the school in providing appropriate education for them. Where the severity of a disability is such as to require a more specialised placement, transfer to a special class or specialist school can be considered.

The additional support which is available to assist schools in catering for pupils with special needs who are enrolled in ordinary classes includes:

- i) Special Equipment, e.g. computer systems, CCTVs
- ii) Support teachers
- iii) Home Tuition/Additional in-school tuition;
- iv) Special Needs Assistant (SNAs).
- v) Vocational Training for people with disabilities carried out under the aegis of the Department of Enterprise, Trade and Employment by FÁS, takes place in integrated settings.

15.1.7 A National Support Service - Planning Group

In January 2000 an initiative to create a national support service for special education was announced by the then Minister for Education and Science (Press Release, 26.1.2000 [HYPERLINK http://www.gov.ie/janmar2000](http://www.gov.ie/janmar2000) www.gov.ie/janmar2000) A number of gaps in the system were identified, i.e.:

- there is little effective co-ordination of services;
- professional services are often seriously stretched; and
- policy development is too often re-active.

An internal Planning Group had already been established to prepare a report on the structures and policies needed to put in place a more comprehensive support service which would:

- Allow for the co-ordination of services;
- Promote integration within schools;

- Provide a local and national information service;
- Ensure expert assessment of needs;
- Establish an objective appeals mechanism;
- Allow for the development and implementation of models of best practice.

As a start to this process seven guiding principles were put forward as a basis for the new service, as follows:

Entitlement: all children with identified special education needs should have entitlement to quality educational services appropriate to their needs and abilities.

Early Identification of Needs: Assessment leading to the identification of special educational needs should be comprehensive and should take place at as early a stage as possible in the child's life.

Promoting Inclusion: Special education services should promote the inclusion of all with special education needs, regardless of disability. The aim of special education provision should be for children/young people with disabilities to share, with their peers, as complete an educational experience as possible.

Review of Progress: The progress of those with identified special educational needs should be tracked and reviewed at regular specified intervals and at key junctures in the educational process.

Continually Update Policy: Policy and practice in the area of special education should be based on consideration of the most up-to-date relevant research and on evidence of best practice both at home and abroad.

A Continuum of Services: As most disabilities encompass a continuum of needs, there should be a continuum of special educational provision in relation to each type of disability.

Right of Appeal: An appeals system should be established to deal with situations where differences of opinion arise in matters of identification and provision between professionals and children/young people and their parents/guardians.

15.1.8 'Our Children - Their Lives' (2000)

The National Children's Strategy 'Our Children - Their Lives' was launched on 13.11.00 by An Taoiseach, Bertie Ahern, TD. The National Children's Strategy aims to improve the quality of children's lives over the next ten years and reflects the provisions of the UN Convention on the Rights of the Child. The Strategy sets out three overall national goals: Children will be given a voice, Children's lives will be better understood and Children will receive quality supports and services.

The Strategy addresses a very broad range of children's issues, including the education of children. The Minister for Education and Science, Dr. Michael Woods, T.D. on 13.11.00 welcomed:

the emphasis in the Strategy on the provision of supports for education, early education, information technology and children with disabilities ... I will ensure that my department implements all of the relevant initiatives in the Strategy and that all children are given the necessary supports to ensure that they receive the best possible education suitable to their needs (Press Release 13.11.00).

A new National Children's Office is being established under Mary Hanafin, T.D., the Minister for Children.

15.1.9 A National Council for Special Education

Following consideration of the Cromien Report, the Minister for Education and Science, Dr. Michael Woods, TD, on 20.6.01 announced government approval for a number of structural reforms of his Department. These included:

The establishment of a National Council for Special Education as a body independent of the Department to provide research, expert advice and to carry out certain operational functions for students with disabilities;

The establishment of a framework of regional offices of the Department of Education and Science.

The Task Force welcomes the decision to set up these new structures. Their establishment is to be overseen by a joint implementation group of the Department of Education and Science and the Department of Finance. In the course of his announcement, the Minister said that at the core of the recommendations in the Cromien Report was *"the absolute need to shift my Department from its overwhelming focus on operational matters to a situation where attention could be given to vital areas of policy development, forward planning and evaluation"* (Press Release, DES, 20.6.2001).

15.1.10 New Government Plans for Special Education

Dr Michael Woods, TD, Minister for Education and Science announced (Press Release 2.8.01) that the Government has approved a range of new measures for the education of people with special needs and disabilities. These include:

A Disabilities (Education and Training) Bill,

A Special Needs Education Forum,

Additional psychologists sanctioned for the National Educational Psychological Service,

A Group on second level education for all children with special needs,

Establishment of the *National Council for Special Education*.

The *Disabilities (Education and Training) Bill* is to be submitted to Cabinet at the beginning of the coming academic year. It is to co-ordinate special education facilities across departments, especially the Departments of Education and Science, Health and Children and Justice, Equality and Law Reform. It will also introduce a number of new programmes as well as enhancements to existing measures and guarantee their delivery for people with disabilities.

A *Special Needs Education Forum* will be convened during the coming year. Interested parties will be invited to participate and the proceedings will help to inform the drafting of the new *Disabilities (Education and Training) Bill*.

An additional 70 psychologists are to be appointed to the National Educational Psychological Service. It was originally intended to have a staff complement of 200 in NEPS by 2004, that goal will now be reached before the end of 2002.

A Group of senior officers has been established in the Department of Education and Science to investigate and to examine existing second level services for all children with special needs and to make recommendations for improvements where appropriate. The Group has been requested to report early in the coming school term.

The *National Council for Special Education* announced on 20.6.01 will be set up this year and is to operate on a full statutory basis as soon as feasible thereafter.

15.2 REVIEW OF POSITION REGARDING POLICY FORMULATION

15.2.1 Introduction

Special needs education in Ireland has from its beginning been organised on the basis of disability categories. Children with disabilities are identified and diagnosed by health professionals. This is described in the literature as a medical

model and requires co-ordination and co-operation between the relevant government Departments and other agencies involved. Since the 1960s and as a basis for policy formulation a number of Commissions, Committees and Task Forces were established by the then Department of Education to examine existing educational provision for children with special educational needs, or in named disability categories, and to make recommendations regarding future provision.

15.2.2 Recommendations not yet fully addressed

The SERC Report (1993) made wide-ranging recommendations regarding the provision of special education for children in fourteen special-needs categories. Many of these have been or are in the course of being implemented. At present the main outstanding recommendations not yet implemented involve:

- provision of services by Health Boards,
- arrangements to ensure equity in relation to the provision of special education to children with disabilities,
- provision of sufficient special capacity, particularly at second level,
- curriculum-needs match for pupils with disabilities,
- outcome evaluation of special provision,
- the organisation within the Department administration of separate special education sections to deal with special provision at level 1 and level 2. (Please see Appendix 20 for actual recommendations.)

The *Report of the Commission on the Status of People with Disabilities* (1996) sought to place services for people with disabilities within a framework of rights. An inter-departmental Task Force prepared a progress report, "*Towards Equal Citizenship*" (1999) on the position as of November 1999 regarding the implementation of the Commission's 402 recommendations. At that time some twenty per cent had been implemented in full and a further forty six per cent were in process of implementation. In relation to recommendations (31, 41, 43, 44, 45) regarding an assessment of needs process underpinned by law, however, the progress report states that:

The Department of Finance cannot accept these recommendations which imply the underpinning by law of access to and provision of services for people with disabilities as a right. This right, if given a statutory basis, would be prohibitively expensive for the Exchequer and could lead to requests from other persons seeking access to

health and other services without regard to the eventual cost of providing these services.

Of the Commission's 402 recommendations, 55 relate to the provision of an education service for people with disabilities. In 11/99 the main outstanding recommendations relating to the provision of an education service not yet implemented were:

- a statutory statement of need, (Recommendation no. 170)
- provision of therapy support services, (Recommendations nos.183-186)
- provision of a curriculum suited to their needs for students with disabilities, (Recommendations nos.191-194)
- the development of links between mainstream and special provision, e.g between mainstream and special schools, or between Vocational Training Centres and mainstream post-primary schools. (Recommendations nos. 198,201)

15.2.3 The Co-ordination Issue

Although the *Education Act* provides that it shall be a function of the Minister for Education and Science to ensure that a level and quality of education appropriate to meeting their needs and abilities is made available to each person resident in the State, the constitutional obligation to provide for free primary education for children is on the State as such. Apart from the Department of Education and Science, services provided by some other government departments, state agencies and voluntary bodies in many cases constitute a vital enabling element in the provision of the education service for children with disabilities. The *Education Act* provides that it shall be a function of the Minister to plan and co-ordinate support services. To varying degrees the question of co-ordination also arises between the Department of Education and Science and the government departments, state agencies and voluntary bodies that have involvement in the provision of education and para-education services and also between the various divisions within the Department of Education and Science.

Reference is made to the need for various types of co-ordination in a number of reports, e.g.

Report of the Special Education Review Committee - SERC Report (1993)

A Strategy For Equality – Report of the Commission on the Status of People with Disabilities (1996)

Ready To Learn- White Paper on Early Childhood Education (1999)

National Support Service for Special Education for Students with Disabilities - Report of Planning Group (2000)

Cromien Report (2000).

A number of arrangements have been put in place to address the issue of co-ordination. Following a recommendation in the SERC Report an Inter-Departmental Co-ordinating Committee with representatives from the then Departments of Education and Health, was established. A progress report on the implementation of the recommendations of the Commission on the Status of People with Disabilities was published in December 1999. The report was prepared by a Task Force comprising representatives of those government departments "under whose remit the implementation of the Commission's recommendations fall". The progress report states that the Task Force, under the aegis of the Department of Justice, Equality and Law Reform, continues to operate and that it has been given responsibility for co-ordinating Government strategy for people with disabilities. In his judgement in the Sinnott case in October 2000 Mr Justice Barr identified "*insufficient liaison between Departments of State*" as a weakness in the State administrative structure.

It is the view of the Task Force that more effective co-ordination is now required. It is noted, however, that the issue of co-ordinating special education facilities across departments is among those to be addressed in the *Disabilities (Education and Training) Bill* that is to be submitted to Cabinet at the beginning of the coming academic year.

15.2.4 Need for a more Pro-active Approach

More recently a number of judgements in the Higher Courts have brought greater clarity to our understanding regarding constitutional rights in relation to the education of children with severe disabilities. While the general Education Act, "*to give practical effect to the constitutional rights of children*" affects many aspects of special educational provision, the approach to the identification and implementation of constitutional rights has not, however, been sufficiently pro-active. This should be included among the issues to be addressed in the new *Disabilities (Education and Training) Bill*.

15.2.5 Resources: Availability and Allocation

In 1998 in its *Strategy Statement -Implementation of the Public Service Management Act 1997*, the Department of Education and Science identified the following among the challenges facing it:

the challenge of meeting the particular and diverse needs of specific groups in society, including those with special educational needs ...

the challenge of securing the necessary human and financial resources to ensure that the Department's objectives and goals can be achieved with professionalism, efficiency and cost-effectiveness.

On the key question of the ability of the Department to meet its challenges the report states:

Achievement of the Department's goals, objectives and outputs is critically dependent on a level of financial and human resources commensurate with the complexity and scale of the tasks involved.

In his judgement in the Sinnott case in October 2000 Mr Justice Barr found that

A citizen's constitutional right must be responded to by the State in full

and

the administrators in the Department of Finance ...appear to be insufficiently informed regarding the constitutional obligations of the State.

The Task Force on Autism considers that meeting the special educational needs of children with disabilities, such as children with ASDs, requires a substantial increase in the level of financial and human resources that has hitherto been made available. The Task Force notes and fully approves the commitment to the provision of additional resources in recent announcements by the Minister.

15.2.6 Issues to be addressed in Policy

In framing policy in respect of an education service for children with disabilities including children with ASDs, the following are among the factors to be addressed, e.g.:

- a. vindication on a pro-active basis of their rights as citizens under the Constitution;
- b. implementation of the provisions of the *Education Act* and all those of other statutes having relevance for their education, including the provisions of the IDEA-1 statute propose din Chapter 14;

- c. arrangements for the identification of their special educational needs;
- d. arrangements for the provision of sufficient specialist expertise and research capability;
- e. arrangements for meeting their special educational needs and for doing so in as inclusive and inobtrusive a manner as can be made feasible,
- f. arrangements for specialised professional development for teachers and for facilitation of different pedagogic approaches;
- g. arrangements for outcome evaluation;
- h. arrangements to ensure justice and equity in relation to the provision of special education to children with disabilities, e.g. as between them and their normal peers, across and within disability categories, in different geographical areas and in Gaeltacht and Galltacht areas.
- i. co-ordination with other government departments which provide services that are essential in building an effective system to meet the special educational needs of children with disabilities. Examples of such services are: identification and diagnosis, therapy-support services and the establishment of a national database of persons with ASDs;
- j. the structure and function of the proposed special needs database vis-a-vis the provision of an education service for persons with an ASD, and making it compatible with WHO systems, e.g. WHODAS II, (See Appendix 21);
- k. resource and personnel implications, including arrangements for the estimation of demand for teacher services generally as a basis for supply planning;
- l. consideration of those recommendations in the various special needs reports commissioned by the Department that continue to have relevance for educational provision for persons with disabilities and that have not been implemented;
- m. giving practical effect to existing policy and to policy announcements that are awaiting implementation;
- n. an appropriate implementation timeframe.

The Task Force welcomes the government decision to establish a *National Council for Special Education*. (NCSE). Given adequate financial and human resources, the Task Force on Autism is optimistic that the NCSE could

eventually provide a structure through which many of the gaps in policy and provision outlined above can be addressed.

15.3 Recommendations

The Task Force recommends:

Policy

1. that the constitutional and statutory rights of children with autistic spectrum disorders and items a-n listed in paragraph 15.2.6 above, be addressed as a matter of urgency in educational policy;
2. that, as announced by the Minister in October 2000, an inter-Departmental team of high-level officials to co-ordinate response to the needs of children with autism be established; that it co-ordinate responses to the needs of all children with an ASD; and that it be given responsibility for overseeing the implementation of the recommendations of this Report;
3. that a report describing existing services and outlining progress in the implementation of policy in respect of special education services, including identification and assessment, for persons with disabilities be published on the web-site of the Department of Education and Science, and updated on a twice yearly basis; that it have particular regard to the provisions of the Constitution and of statute law and, in relation to the education of persons with an ASD, to the seven guiding policy principles adopted in January 2000 by the then Minister as a basis for the service (see par. 5.1.8), the recommendations of the *Task Force on Autism* as contained in this Report and the outcome during the preceding six months of any legal proceedings regarding educational provision for persons with an ASD;
4. that the database project “*to identify special needs of pupils and support the development and implementation of policy*” as announced by the Minister on 9.3.2000 be proceeded with as a matter of urgency, that it be compatible with WHO systems, e.g. WHODAS II, that it be updated annually and appropriately co-ordinated with similar initiatives in other Government Departments and State agencies;
5. that the improvements to the education service for children with autism announced in October 2000 be implemented in respect of all children with an autistic spectrum disorder;

6. that the definition of "*Autistic Spectrum Disorders*" currently used by the Department of Education and Science (par. 5.1.2) be updated to read as follows:

A suitably qualified professional or professionals will have assessed and diagnosed such students as having an autistic disorder, childhood autism, pervasive developmental disorder- not otherwise specified or Asperger's Syndrome, according to the criteria of DSM-IV-TR, ICD-10 or an equivalent diagnostic system.

7. that key stakeholders, and parents in particular, be consulted in the development of educational policy in respect of children with an ASD.

CHAPTER 16

COSTS AND BENEFITS OF EDUCATIONAL INTERVENTION FOR PERSONS WITH AN ASD

16.1 INTRODUCTION

This Chapter gives consideration to the issue of the costs and benefits to persons with ASDs and their families, to society and to the economy of investing in educational provision and services. It begins with reference to the present position as reflected in submissions made to the Task Force on Autism and as reflected in the judgement of Mr. Justice Barr in the Sinnott Case. It then sets out the economic case for educational intervention.

16.2 THE PRESENT POSITION

Investment in services for persons with ASDs involves considerable care and planning on the part of the State. As we have shown in Chapter 2, there is an increase in the prevalence of ASDs, with up to circa 6,700 young persons with ASDs in the 0-19 age-group likely to be in need of service over the coming years, albeit with very varying levels of need. The need for long term planning of services was dealt with in eight of the submissions to the Task Force, as well as being implied in many more.

Co-ordination of services was also seen to be closely linked to planning and investment. Observations are made in twelve submissions about the need for co-ordination and communication among State Departments and agencies. The need for co-ordination between the Department of Health and Children, and the Department of Education and Science, was mentioned in ten of these twelve submissions. The comments focus on the need for structures of co-ordination and communication at both national and regional level and between agencies of the DES. Concern for an even level and quality of service throughout the country was expressed. The thrust of the comments is typified in this extract:

The most frustrating thing for us as parents is that there is no clear co-ordinated approach to these matters by the State. Things seem to happen almost on an ad hoc basis. From talking to other parents of children with autism around the country, it seems you can be lucky or unlucky with the services available in your area, but also with the quality of service providers which can vary considerably. One is constantly 'grasping at straws.' You hear of a new therapy or treatment by chance and you go off after that in the hope that it will help.

The disquiet with the level of investment, and lack of planning, evident in the submissions needs to be addressed. Planning should be innovative, pro-active, and should involve the Department of Education and Science, The Department of

Enterprise, Trade and Employment and the Department of Health and Children, and should be supported by adequate levels of expenditure. It should be 'person-friendly and family-friendly.' Current inequities in provision which arise primarily by virtue of the quantity and quality of provision in the area of residence of the person with an ASD must be addressed and guidelines for provision issued to both major Departments of State with obligations to provide services to children with ASDs – i.e. to the Departments of Health and Children, Enterprise, Trade and Employment and Education and Science. With regard to the planning and administration of the system, and to the provision of financial resources by the State, in his High Court judgement in the Sinnott case, Mr Justice Barr was in no doubt about the present position:

It is established that the primary weakness in our administrative structure which has given rise to the plaintiffs' claims is twofold. First, insufficient liaison between Departments of State where a particular problem involves two or more of them ... Secondly, the administrators in the Department of Finance, who play a major role in advising on the dispositioning of the financial resources of the State, appear insufficiently informed regarding the constitutional obligations of the State to the weak and deprived in society to enable them to assess realistically the degree of priority which the State should devise in meeting its constitutional as distinct from non-constitutional obligations ... Needs should be met as a matter of constitutional priority and savings, if necessary, should be made elsewhere (The High Court Judgement Delivered by Mr Justice Barr on the 4th Day of October 2000, pp. 25-27).

Where the State chooses to fulfil its obligations through third party organisations (e.g. voluntary service providers), Mr Justice Barr recommended that it take a hands-on approach and a positive role in the organisation, provision and supervision of services offered on its behalf and also to provide the funds necessary to meet its constitutional obligations where they are contracted out in that way (ibid.).

It should be clear from our comments throughout this Report, and from the comments of Mr Justice Barr in his High Court Judgement, that the prime focus in educational decision-making and provision should be on the needs of the person with an ASD. There are costs associated with meeting the needs of people with ASDs and these must be faced by society and by the administrators in a range of government departments, in particular in the Departments of Finance, Education and Science, Enterprise, Trade and Employment, and Health and Children. It is invidious and unjust to make decisions based primarily on provision at the lowest cost, rather than on individual need, when it comes to the education of a vulnerable and marginalised group such as persons with autistic spectrum disorders.

16.3 COSTS AND BENEFITS

Educational expenditure in Ireland as a percentage of the Gross National Product has grown immensely since the 1960s. However, it is now time for a significant outlay of resources on the educational needs of people with autistic spectrum disorders in Irish society.

Autistic spectrum disorders are lifelong developmental disabilities that affect the way a person communicates and relates to people around them. It has been estimated that, currently, approximately sixty per cent of children with typical autism will grow up to be dependent on adults in all aspects of life (Jarbrink and Knapp, 2001). Just below ten per cent of children with autism do very well in adult life. Children diagnosed with Asperger's Syndrome tend to do better as adults than those with classic autism but without support they may be at increased risk of depression, alcohol problems and suicide in adolescence (Mental Health Foundation News Release, 2000, pp. 27-28).

A significant body of international research on autism has demonstrated that high-quality, early and on-going, work with children with ASDs and their families can produce improvements in communication and social understanding (see earlier Chapters of this Report). Such appropriate, high quality, ASD-specific educational programmes, implemented from diagnosis onwards and based on the individual needs of the child, are highly cost effective, as argued below. Therefore, in addition to compelling arguments for investment in education and inclusion based on equity and social justice, there is an economic rationale for such a policy.

16.4 THE ECONOMIC CASE FOR INTERVENTION

Far too little attention has been given to date to the economic case for intervention in the case of people with ASDs or similar difficulties. The basic point is that appropriate interventions, particularly from an early age, can have significant positive benefits for those with ASDs in terms of language, communication, social behaviour, developmental rates and IQ, educational attainment and greater employment opportunities (Howlin and Rutter, 1987; Rogers, 1996; Jacobson et al. 1998; Mawhood and Howlin, 1999). Such early intervention may reduce the level of intensive ongoing support, in relation to a range of services, resulting in significant savings to the State. In other words, failure to provide appropriate adequate intervention from an early age will simply result in increased ongoing costs to the exchequer at a later stage and for a longer period. This represents, in effect, a significant 'opportunity forgone' (often termed 'opportunity cost' by economists) by the individuals concerned, their families and society in general.

Some important new research on autistic disorder in Britain further strengthens the economic case for intervention (Jarbrink and Knapp, 2001). This provides detailed estimates of the costs of a whole range of services for those with autistic disorder. Assuming a prevalence of only five per 10,000 in the population (a gross underestimate, as we point out in Chapter 2), the annual cost of autistic disorder in Britain is estimated by Jarbrink and Knapp to be almost £1 billion (sterling) while the lifetime cost for an individual, depending on levels of disability, ranges from £784,800 for those with high functioning autism to £2,940,500 for those with autism and an additional learning difficulty. Since they argue that the vast majority (at least seventy per cent of those with autistic disorder they suggest¹) can be assumed to be in the latter category, the overall average lifetime cost per person with autism is estimated to be £2.4 million. It is clear from the submissions to the Task Force and from other

¹ The data presented in this table by Jarbrink and Knapp (2001) does not refer to those with Asperger Syndrome, but to those with classic autism (autistic disorder), including high functioning autism (HFA).

available evidence that the financial allocations to people with ASDs in Ireland are nowhere near those in Britain, clearly indicating a significant per capita expenditure gap which Ireland would have to bridge if it is to fulfil its constitutional obligations and aim even for equality with Britain.

The costs for autistic disorder identified by Jarbrink and Knapp (2001) in Britain include hospital services, other health and social services, residential care, voluntary support, special education, medication, sheltered work, day care provision, productivity losses for those with autism, the cost to family members in terms of earnings foregone and other essential family expenses such as adaptations and special equipment. The details are given in Table 1.

Table 1. Average Lifetime Costs for People with Autism (Autistic Disorder)

	<i>Autism with additional Learning Difficulty</i>	<i>%</i>	<i>High Functioning Autism</i>	<i>%</i>
	£		£	
Hospital services	26,600	0.9	30,700	3.9
Other health/social services	71,600	2.4	31,200	4.0
Residential support	2,134,000	72.6	312,500	39.8
Voluntary support	16,800	0.6	-	-
Special Education	179,100	6.1	108,300	13.8
Medication	3,400	0.1	8,300	1.1
Sheltered work	16,200	0.6	67,800	8.6
Day activities	422,400	14.4	74,500	9.5
Lost productivity	-	-	137,100	17.5
Family members cost	39,600	1.3	14,400	1.8
Family expenses	30,800	1.0	-	-
Total	2,940,500	100.0	784,800	100.0

Source : K. Jarbrink and M. Knapp, 'The Economic Costs of Autism in Britain', *Autism*, Vol. 5, No. 1, 2001, pp. 7-22.

It may be noted in Table 1 that residential lifetime care in Britain for those with autism and an additional learning difficulty currently costs, on average, £2.1 million (sterling) per person or 72.6 per cent of the total. Day activities are next in order of magnitude and cost £422,400 per person or 14.4 per cent of the total. These two categories account for the vast brunt of expenditure. This is in comparison with only a lifetime expenditure of £179,100 or 6.1 per cent of the total for special education and a mere £16,200 or 0.6 per cent of the total for sheltered work. In the case of high functioning autism, it is interesting to note that an increase in the proportion (to 13.8 per cent) allocated to special education (though at a significantly lower lifetime cost per person) and sheltered work (increased to 8.6 per cent) is associated with a much lower cost for residential care (£312,500 or 39.8 per cent) and day activities (£74,000 or 9.5 per cent). As an example, Jarbrink and Knapp (pp. 18-19) estimate that, if a

person with autistic disorder were enabled to live in a sheltered residential setting and to attend a sheltered workshop in adulthood instead of living in residential care and attending a day centre, the lifetime savings could be about £148,000 (sterling).

The average lifetime costs for people with Asperger's Syndrome are estimated by Jarbrink and Knapp at St£525,070 (Borrill, 2000). This somewhat smaller figure may reflect the fact, inter alia, that more than 75 per cent of children with Asperger's Syndrome are able to attend mainstream schools. The greatest costs are for living support (70 per cent) and day activities (14 per cent); much less is spent on education (7 per cent). The unit cost of running a supported employment scheme for people with high functioning autism and Asperger's has been estimated as £388 per month per client (Mawhood & Howlin 1999). The evidence from this study suggests that even moderate increases in educational provision could potentially result in major savings in later living costs (ibid).

These cost/expenditure estimates have very important economic implications. They suggest significant savings to the state if functioning can be improved for the majority who have learning difficulties. They also indicate that a much greater emphasis and expenditure on special education and sheltered employment, while not eliminating dependency on residential care and day activities, would reduce expenditure significantly on these categories and effect a reduction in overall costs.

This study indicates that further information is needed on the costs to *families* of having a child with an ASD, and of the overall costs of ASDs, including AS/HFA. The economic consequences to parents of having an autistic child living at home include an annual loss of earnings estimated as at least 1/6th of the average disposable income (ibid.). Further information is needed on the costs to families of having a child with autism, and on the economic costs of high-functioning autism and Asperger's Syndrome. To date no such research has been conducted in Ireland. Such research is needed as part of the ongoing development of services in Ireland.

16.5 RECOMMENDATIONS:

Throughout the Chapters of this Report of the Task Force, recommendations are made for the establishment of an appropriate and adequate education and support system for persons with autistic spectrum disorders. Not all of these recommendations have funding implications but many of them do. Recommendations which directly relate to the costs and benefits of the most major of these initiatives are included below.

The Task Force recommends:

Policy

1. that priority be given to resourcing and implementing the educational services for people with ASDs, from the point of diagnosis, so that the long-term consequences of the investment in these people may accrue to their personal development and equality of status in Irish society; that funding be forthcoming to provide the specialist

resources and equipment necessary to meet the needs of all children/students with an ASD, so that their individual interests and strengths can be maximised.

2. that the needs of persons with an ASD be met as a matter of constitutional priority and savings, if necessary, be made elsewhere; that the costs associated with meeting the needs of persons with autistic spectrum disorders be faced by society and by the administrators of the education system; that where services are contracted out by the State to third party organisations, the State provide the funds necessary to meet its constitutional obligations; that where responsibilities shift from one Department to another there be a commensurate movement of resources from one Department to another; that there be close co-ordination between Departments in the delivery of services;
3. that current inequities in provision, which arise primarily by virtue of the quantity and quality of provision in the area of residence of the person with an ASD, be addressed and guidelines for provision issued to the two major Departments of State with obligations to provide services to persons with ASDs – i.e. to the Departments of Health and Children and Education and Science;
4. that funding be made available, through the Departments of Education and Science, Enterprise Trade and Employment, and Health and Children, to ensure that the gains of education are built upon through continuing education and supported employment initiatives;

Practice

5. that research be conducted in Ireland into the costs and benefits of early and on-going educational intervention for persons with ASDs.

CHAPTER 17

RECOMMENDATIONS

This Chapter includes all of the recommendations of the Report, listed according to Chapter. They are divided, where relevant, into those which refer primarily to *policy* (i.e. where action must be taken by Government or by Departments of State) or to *practice* (i.e. where actions and/or approaches are indicated for educational institutions). There are a number of recommendations throughout which do not fall neatly into these subdivisions, however. Where this has been the case the recommendation has been listed under the predominant heading. Chapter 1 is introductory and thus no recommendations arise.

CHAPTER 2: AUTISTIC SPECTRUM DISORDERS

The Task Force recommends:

1. that as a matter of urgency research be conducted into the national prevalence of autistic disorder;
2. that as a matter of urgency research be conducted into the national prevalence of Asperger's disorder;
3. that the Departments of Education and Science, and Health and Children, establish compatible databases on children and adults diagnosed with autistic disorder and on children and adults diagnosed with Asperger's Syndrome;
4. that the Departments of Education and Science, and Health and Children, agree a prevalence rate for ASDs as a basis forward planning in the provision of services and to ensure that resources will be sufficient; prevalence estimates indicate that, as an initial target, provision be made for services for at least 20 per 10,000 with autistic disorder and for 36 per 10,000 Asperger's Syndrome;
5. that forward planning by the Government be based on international prevalence rates, until our national ASD data bases are fully operational.

CHAPTER 3: PARENTS AS PARTNERS

The Task Force recommends:

Policy

1. that the Recommendations of the *Report of the Commission on the Status of People with Disabilities (1996)* outlined below, regarding the roles, responsibilities and rights of parents be implemented without further delay:

Parents have primacy in the decision making process as soon as their child has been identified as having particular educational needs. They [and the child whenever appropriate] must be entitled to make an informed choice on the educational placement of their child, (11.8, principle 5, p.173).

...The legal rights, roles and responsibilities of parents must be clearly outlined in relation to any assessment or decision making process and should reflect the constitutional rights of parents in the matter of the child's education (11.14,p.175).

...Parents must be acknowledged as full and equal partners throughout the educational process and be provided with guidance and support, full information about their child's progress, and be allowed to contribute meaningfully to it (11.19, p. 176).

Consultation with people with disabilities and their representative organisations must be a key feature of future policy formation ... (11.20, p. 176);

2. that the role of parents as advocates for their children/young adults with autistic spectrum disorders be formally recognised;
3. that structures be established to ensure that the provision of support services and therapies are delivered smoothly and seamlessly;
4. that a national forum for autistic spectrum disorder be established to facilitate the dissemination of information and exchange of views between parents, professionals and government departments;
5. that the Department of Education & Science initiate a Parent-School Partnership Scheme for persons with autistic spectrum disorders; that this entail the creation of Partnership Facilitator posts;

Practice

6. that consultation, collaboration and the inclusion of parent representatives/voluntary and support organisations on policy/planning teams and committees at local and national level be recognised as a key feature of future policy formation for ASDs; that professional input and training be provided to such parent representatives/organisations as appropriate;
7. that persons with Asperger's Syndrome/High functioning autism have the opportunity and be actively encouraged to participate on health/education planning committees;
8. that parents be informed of their entitlement to attend all meetings and case conferences concerning their children, including those where the progress or intervention of their child may be under deliberation; that advance notice of such meetings be supplied to parents to facilitate attendance;
9. that emphasis be placed on the centrality of parents in decision making relating to their child with an ASD.

CHAPTER 4: IDENTIFICATION, REFERRAL AND INITIAL ASSESSMENT

The Task Force recommends:

Policy

1. that the Departments of Education and Health co-ordinate a National Asperger's Syndrome/High Functioning Autism Awareness Campaign aimed at teachers, parents and the medical profession in an effort to combat current low levels of awareness and identification rates; that awareness be raised among professionals of the need for referral of suspected cases of AS/HFA to the appropriate secondary or tertiary services; that special training be provided within the relevant professions in relation to AS/HFA;
2. that a National ASD screening programme be established targeting Public Health Nurses and General Practitioners;
3. that Health Boards establish procedures for the assessment of possible ASD in the siblings of identified children;
4. that all Health Board and Department of Education and Science funded assessment and diagnostic services operate with uniformity; that they establish a defined template to follow; that this protocol include:

- a requirement that all staff have appropriate training in ASDs;
 - diagnostic and follow-up assessments which are offered to people of all ages, where relevant;
 - the provision of this service within a fixed time frame;
 - use of up to date and accepted criteria for diagnosis;
 - the ensuring of regularly monitored quality assurance systems and performance standards, which include the feedback of service users;
 - systems and standards which are regularly monitored and evaluated, based on numbers diagnosed annually, time scales for definite diagnosis, user satisfaction, and systems of referral;
 - further assessment(s) and/or independent second opinions to be available where there are concerns regarding definitive diagnosis, the presence of additional disorders, or disagreement amongst the primary parties;
 - a comprehensive paediatric assessment, which includes the investigation of autism-related conditions and symptoms, and is conducted as a matter of course;
5. that the Child, Adult and Family Support Plans, and Statement of Educational Needs be afforded Statutory status (including statutory entitlement to the provision of an IEP); that an IEP be established for each individual, based on the results of relevant assessments;

Practice

6. that relevant professionals and diagnostic services come together to establish agreed AS/HFA and autism assessment procedures; that they ensure continuity by using up to date and agreed diagnostic criteria for the accurate and early identification of classic Autism, Asperger syndrome, and PDDNOS;
7. that the assessment and service provision functions be independent of each other and that the assessment process is transparently free of any vested interest;
8. that following receipt of an ASD diagnosis, intervention commence within 30 days; that additional assessments needed be conducted over the first 3-6 months.
9. that parents have access to accurate information regarding mainstream and specialised educational options for the placement of their children post diagnosis;
10. that information on a variety of empirically validated methodologies be available to parents; that the values underpinning differing approaches be

explored from the professional and parental perspectives before making decisions on educational placements;

11. that Speech and Language Therapy training programmes include a module on differential diagnosis (Language disorder / ASD) so that Speech and Language Therapists may more effectively refer for comprehensive assessment where indicated.

CHAPTER 5: GENERAL EDUCATIONAL ISSUES

The Task Force recommends:

Policy

1. that the Minister of Education recommend to the Minister of Health and Children, the introduction of Statutory Child and Adult Family Support Plans for those with an ASD;
2. that formal behavioural guidelines for staff be developed by the Department of Education and Science, in collaboration with parents, the Health Boards, and relevant voluntary/non-governmental organisations and distributed to all schools and institutions catering for persons with ASDs;
3. that no student should be suspended or expelled from their educational programme due to behaviours resulting from the severity of their disability;
4. that schools and programmes educating one or more students with an ASD are properly resourced;
5. that formalised Department of Education and Science-University partnerships be established to develop appropriate programmes for persons with ASDs;
6. that a Visiting Teacher Service, similar to the Visiting Teacher Service for children with impaired hearing and with a high level of very specialised training in the area of Autistic Spectrum Disorders, be put in place for persons with ASDs;

Practice

7. that the Department of Education and Science instruct and resource the In-Career Development section of the Department to prioritise the training of all staff involved in the education of students with ASDs to insure their

- understanding of how the particular ASD and any accompanying disorder affects the student's learning style;
8. that schools providing for persons with ASDs implement the Statementing procedure and detailed individual education plans which respond to the needs of the child and provide for education in the least restrictive setting;
 9. that extreme caution be exercised when deciding who should be informed about the diagnosis of Asperger Syndrome, and that the dignity and decision of each person regarding disclosure / non-disclosure of disability status among peers be respected;
 10. that the marginalised lifestyles and social isolation of those with ASDs be acknowledged through pro-active policies that promote social inclusion, positive mental health and community integration; that such strategies be prioritised and funded for late adolescents/adults with AS/HFA in the 'mainstream' who are without a dedicated service provider and at risk of social isolation/depression through lack of social opportunities;
 11. that the Department of Education and Science introduce Behaviour Support Teams in each region to support the education of children with ASDs and additional behavioural difficulties;
 12. that a range of suitable options be developed, so that students presenting with significant behavioural challenges will remain in a suitable educational programme, un-interrupted, while simultaneously supporting the staff who are charged with educating them;
 13. that all persons diagnosed with AS/HFA have access to age-appropriate social, communication and life skills training programmes across the range of educational settings; that where diagnosis is made during adolescence / adulthood, intervention programmes i.e. peer support groups/ social understanding initiatives should be implemented immediately;
 14. that Gardai and Probation Officers be aware of AS / HFA and respond to it sensitively; that it be part of pre-service training at Templemore training college, and part of inservice training in the Probation Department;
 15. that research be carried out on methodologies and approaches; on the benefits of various clinical interventions; on the development of ASD-specific components of teacher and classroom assistant training; on curricular interventions; on inclusion in education for persons with ASDs; on strategies for successful mainstream education; and that there be systematic evaluation of all pilot projects.

CHAPTER 6: EDUCATIONAL APPROACHES

The Task Force recommends:

Policy

- 1. that the Department of Education and Science make available a range of approaches and therapies to meet the unique needs of each student with an ASD; that such provision includes, as appropriate, a choice/combination of home based, mainstream or specialist settings and the various core therapies of speech and language and occupational, and behavioural and physiotherapy when specified;**
- 2. that a range of resources to meet the unique needs of each student with an ASD in all schools settings be provided by the Department of Education and Science; that this include appropriate adaptations to the curriculum, in-school/home counselling support, IT funding, youth club support, and holiday and after-school schemes;**
- 3. that funding be made available for research into the effectiveness of various approaches and strategies used to support students with ASDs, including the specific curricular approaches to promote the academic potential and social and emotional progress of children with AS/HFA;**
- 4. that the Department of Education and Science issue a national ASD policy directive which will emphasise the primacy of the principles of inclusion and the least restrictive environment, and which will require schools to include a statement of provision and curriculum access and support for persons with an ASD within the School Plan;**
- 5. that the Department of Education and Science establish a committee, which will include parent representatives, to develop agreed guidelines and procedures for monitoring children's progress;**

Practice

- 6. that schools enrolling students with ASDs ensure a 'whole school' ethos conducive to appropriately supporting the needs of these students;**
- 7. that schools enrolling students with ASDs ensure that there is a written policy indicating the arrangements, including assessment and recording procedures, teaching approaches, support services, child safety provision,**

- and staffing and material resources, to support successfully the needs of these students;
8. that schools enrolling students with ASDs actively promote inclusion for these students.
 9. that the Department of Education and Science identify and circulate a formal standard policy and guidelines on anti-bullying; that anti bullying policies and pro-active protection strategies are implemented, that bullying prevention, and how to respond to this issue, form part of teacher education, particularly for students with AS / HFA
 10. that the Department of Education, through the inspectorate, SNOs or otherwise, take responsibility for the identification, training arrangements and employment of teachers to support students with AS/HFA who are availing of the Home Tuition scheme and also, for the employment, training and employment of the proposed Visiting Teachers for persons with ASDs .
 11. that community integration/ education and transport arrangements for adolescents with AS / HFA be age- and ability-appropriate, and arranged with due respect to the right of each individual to retain confidentiality regarding disability status among peers; that, where relevant and appropriate, grant support in lieu of special transport be provided in order to retain confidentiality;
 12. that the Departments of Education and Health should encourage, support and provide funding for young people with AS/HFA to join local Gyms and Health Centres, particularly during holidays, in an effort to maintain/improve community integration, and their physical and mental health through the provision of positive social opportunities

CHAPTER 7: EARLY EDUCATION

The Task Force recommends:

Policy

1. that the State put significant resources into the development and implementation of intensive early services programmes for children on the Autistic Spectrum;
2. that the Department of Education and Science, in conjunction with the Health Boards and in consultation and agreement with parents, develop

- protocols for nationally agreed intervention models to be developed in each region;
3. that educational (i.e. under the Department of Education and Science) and independent clinical (i.e. under both the Department of Education and Science and Health Boards) assessment and intervention be offered from the point of diagnosis;
 4. that special classes specifically developed for children with an ASD aged five and under, be established in mainstream and some special schools, and that these be differentiated on the basis of need and level of functioning;
 5. that the home tuition scheme be re-organised to accommodate the needs of the very young child with an ASD;
 6. that children be allowed dual enrolment, i.e. in a mainstream setting as well as a specialist ASD class;
 7. that statements of educational need, individual educational plans, and child and family support plans be developed for the young child;
 8. that individual, ongoing, multi-professional assessment be offered to establish effective, sequentially ordered intervention programmes;
 9. that the Department of Education and Science Inspectorate play an active, well defined role in the promotion, monitoring and evaluation of ASD early services programmes;
 10. that the Department of Education and Science form partnerships in order to adequately resource and support a range of existing preschools and to provide integrated preschool experiences for children from the point of diagnosis to five years of age, with ASD-specific supports funded by the Department of Education and Science; that a set of standards, guidelines and monitoring procedures be defined to accompany this development;
 11. that formal links between the Department of Education and Science, Health Boards and Universities with Education and Psychology Departments be established for the purposes of developing appropriate early education for children with ASDs;
 12. that NEPS be authorised to become involved with preschool and early services programmes;

Practice

13. that supports be provided as needed for children with an ASD when in a mainstream setting;
14. that the Visiting Teacher for ASDs Scheme, suggested in this Report, be available to children with an ASD in all preschool settings;
15. that special pre-school classes offer validated approaches of teaching children with an ASD;
16. that the Department of Education and Science provide the staff necessary to conduct home and school programmes, including intensive behavioural intervention where and to the extent indicated; that this could be conducted in approach specific (e.g. Applied Behavioural Analysis) schools or classrooms;
17. that prescribed therapies and behaviour management support be made available, and delivered as agreed on the Support Plan or IEP, regardless of where the child receives his/her education;
18. that formal review be conducted at least annually at this age;
19. that the NEPS be involved, in collaboration with the relevant Health Board psychologist, in the placement and subsequent monitoring of children aged 5 years and under who have an ASD;
20. that independent evaluation research on pre-school programmes funded by the Department of Education and Science be conducted to inform future planning and provision.

CHAPTER 8: PRIMARY EDUCATION

The Task Force recommends:

Policy

1. that provision for children with ASDs be sufficient to meet the demands in all geographical regions and be based on admission criteria which reflect diagnostic category, assessed needs and parental choice;
2. that differentiated provision be made available for various needs of pupils within the spectrum, irrespective of the timing of diagnosis, and sufficiently flexible to allow the child with an ASD to avail, where necessary, of different placements as outlined at 8.4.1;

3. **that enrolment in classes for children with AS/HFA will be based on average intellectual ability and cognitive functioning in accordance with DSM IV diagnostic criteria for Asperger syndrome;**
4. **that the function of ‘special needs co-ordinator’ be assigned to a named teacher in each school;**
5. **that provision for children with ASDs ensure appropriate opportunities for meaningful integration/inclusion with their similarly aged peers and be written into the school plan;**
6. **that the Department of Education and Science secures sufficient support services for children with ASDs;**
7. **that Special Needs Assistants for students with ASDs be adequately trained in ASD-specific interventions and remunerated appropriately;**
8. **that a review of the progress and the Individual Education Plan for each child with an ASD be carried out annually or at the appropriate request of a parent or teacher;**
9. **that there be a full, independent, multi-disciplinary assessment to effect the smooth transfer of the children from the primary sector to the second level sector;**
10. **that children with ASDs in primary schools have full access to the curriculum of their similarly aged and ability peers, with appropriate modification, as identified by the relevant Statement of Need and Individual Education Plan;**
11. **that pupil/teacher ratios should continue to remain small, as for early education, and responsive to individual needs;**
12. **that the Department of Education and Science inspectorate regulates and annually reports on primary provision for children with ASDs;**

Practice

12. **that schools review, at least annually and in the context of the school plan, their provision for children with ASDs in order to inform practice and make improvements.**
13. **that schools actively support and involve parents of a child with an ASD in all aspects of the education of their child;**

14. that schools facilitate and encourage staff to undertake continuing in-career development in order to respond effectively to the needs of children with ASDs.

CHAPTER 9: SECOND LEVEL EDUCATION - ASSESSMENT, PROVISION, CURRICULUM, TEACHING METHODS AND SUPPORT SERVICES

The Task Force recommends:

Policy

1. that there be a flexible continuum of educational options for pupils with ASDs at second level;
2. that there be a range of differentiated models of provision for ASD in respect of the two categories of classic autism and AS/HFA;
3. that following the multi-disciplinary assessment to be carried out prior to completion of the primary stage, the proposed Special Needs Organiser or appropriate Department of Education and Science officer have the responsibility, with parental agreement, for identifying and securing an appropriate post-primary placement for students with ASDs;
4. that entitlements/supports attached to each child, subject to appropriate modification, be automatically transferred to the next educational setting;
5. that any additional resources allocated to a pupil with an ASD be ring-fenced in respect of that pupil;
6. that support services be fully accessible to all pupils with ASDs, irrespective of whether their educational placement is in home-based, mainstream or special settings;
7. that the Department of Education and Science issue and circulate written guidelines outlining the necessity of regular home/school liaison in respect of students with ASDs;
8. that the Department of Education and Science urgently reviews the practice of attaching explanatory notes regarding special arrangements in Examinations to the candidate's certificate of results;
9. that there be a significant increase in projected NEPS staffing levels to enable the educational psychologists to have a meaningful role in working with pupils with ASDs;

10. that the Department of Education and Science produce and circulate guidelines on bullying to schools;
11. that the effectiveness of provision for students with ASDs in second level schools be regularly monitored and annually reported on by the Department of Education and Science Inspectorate;

Practice

12. that second level placement recommendations be based upon a 'least restricted environment' philosophy and a presumption of local provision;
13. that all post primary students with ASDs have access to the most appropriate curriculum and accreditation route to match their ability and direction;
14. that the proposed Visiting Teacher Service for ASDs continue to play an important function in supporting pupils with ASDs at second level;
15. that preparation and planning for post second level education be a basic component of the student's individual education plan at second level;
16. that a review of the post second level transition plan take place at approximately fourteen years of age, or not later than the end of the Junior Cycle stage;
17. that a comprehensive independent multi-disciplinary assessment be carried out on all pupils with ASDs as they approach the completion of post primary education;
18. that the discrepancy between ability and attainment in students with AS/HFA be researched, with a view to identifying effective interventions designed to address this problem;
19. that particular attention needs to be devoted to providing support systems, including counselling, for all students with ASDs, which will, in particular, increase the likelihood of retaining students with AS/HFA at second level;
20. that all persons diagnosed as AS/HFA have access to age appropriate social, communication and life skill training programmes across the range of educational settings;
21. that the social and educational needs of students with AS/HFA at second level be prioritised by all those providing services to this category.

CHAPTER 10: THIRD LEVEL AND CONTINUING EDUCATION

The Task Force Recommends:

Policy

1. that joint interdepartmental policy be developed to ensure the smooth planning and delivery of a continuum of multi- departmental support services to meet the education, training, intervention, accommodation and social needs of late adolescent/adults with ASDs as outlined throughout this chapter;
2. that services for persons with ASDs proceed on a basis of partnership between the Departments of Health and Children, Trade, Enterprise and Employment, Social, Community and Family Affairs, Finance, and Education and Science;
3. that improvements in the participation, retention and completion rates of students with AS / HFA in post leaving certificate, further, and third level education courses be targeted as an urgent priority; that this priority be addressed by the allocation of additional resources and flexible support structures (as outlined at 10.7.11) across the range of post secondary mainstream education settings;
4. that the concept of *lifelong learning* be implemented in practice through the availability of educational support in *the least restrictive environment* throughout the lives of persons with ASDs;
5. that funding be attached to the individual (transport, accommodation, course fees,) for persons with AS/HFA who participate in mainstream education and are, therefore outside the remit of dedicated service provision;

Practice

6. that the educational needs of adolescents/adults with ASDs be addressed through a Statutory Statement of Needs and a Statutory ASD Adult & Family Support Plan;
7. that compensatory vocational training and continuing educational initiatives, and interim measures be established to meet the education and training needs of persons with ASDs who have been excluded, or dropped out of the education system due to lack of support;

8. that all school leavers with ASDs be provided with flexible support and adequate opportunities to participate in age and ability appropriate education / training options, as identified by the transition assessment process, and outlined at 10.7.22 of this chapter;
9. that Post Leaving Certificate, Further/Adult Education and Third-level student support schemes for persons with AS/ HFA be implemented throughout the country on a regional basis; that the Department of Education issue an information pamphlet outlining the range of entitlements (e.g. educational assistance, disability funds, and supports) available to persons with disabilities who wish to pursue Post Leaving Certificate, further/adult and third level courses;
10. that AS/HFA specific Counselling Services be developed as a matter of urgency in all further/adult and higher educational institutions;
11. that immediate steps be taken to identify and deliver appropriate transition and on-going post-secondary support to those people with ASDs who are in mainstream education and outside the provision of dedicated service providers;
12. that the use of Assistive Technology in supporting learning be facilitated and encouraged; that grants for computers be forthcoming as there is evidence that many of those with AS / HFA find this medium of communication beneficial;
13. that the Departments of Education and Health develop a one hour overview and information/awareness package on AS/HFA for distribution to post secondary, further/adult and third level institutes;
14. that dedicated training provision to meet the needs of late adolescents/adults with AS/HFA be developed; that such AS/HFA specific initiatives, would ideally incorporate links with local colleges, and the work place, while addressing core social understanding /communication skills in conjunction with career guidance and vocational skills;
15. that sheltered day rehabilitative and vocational training initiatives for adolescents/adults with ASDs should ideally operate with specific objectives within a limited time frame, and should incorporate external monitoring and review procedures;
16. that Supported Employment schemes be developed on a National basis to replicate the existing Asperger Syndrome model (the Dublin South Supported Employment Initiative) with additional ancillary supports provided through the ASD intervention services;

or

- that each ASD Health Board Intervention Service (or service provider with responsibility for late adolescents/adults with ASDs) include a supported employment specialist/ ASD trained job coach as part of the core intervention team.
17. that sheltered housing and supported/semi-supported accommodation in the community be provided in conjunction with out-reach schemes which enable people with ASDs to live in homes of their own if they so choose;
 18. that the role of ASD intervention coordinators include close collaboration with the proposed regional Special Needs Organisers and VEC Adult Education Officers, to develop and sustain links with the proposed AS/HFA dedicated training initiatives and vocational training provision (e.g. FAS, CERT, etc..) and further/adult and third level institutions and colleges.
 19. that, in situations where existing further vocational or third level programmes prove to be too academically oriented for lower-functioning pupils, FETAC (Further Education and Training Awards Council) provide appropriate alternatives.

CHAPTER 11: CLINICAL AND SUPPORT SERVICES

The Task Force recommends:

Policy

1. that the Interdepartmental Co-ordinating Committee, already established to clarify and define the distinct roles of each Department, identify and ensure delivery of a range of ASD services, and secure sufficiency of staffing at local and national level to meet the expected needs of persons with ASDs in Ireland;
2. that speech therapists and other support services as required are made available in schools and other educational settings by the Department of Education and Science;
3. that the Department of Health and Children implements the initiatives identified within the Report of the Expert Group on Allied Health Professionals;

4. that local committees co-ordinated by the Health Board ASD Co-ordinators and the proposed Department of Education and Science Special Education Needs Organisers be established and liase formally to secure the smooth management and administration of ASD health and education services at local level;
5. that independent regional diagnostic assessment and intervention services for ASDs be set up in each Health Board area; that where the required clinicians are not available on the team, full effort should be made to contract with local private practitioners;
6. that an ASD specific service be set up in all Health Board areas to ensure that all persons with an ASD across the range of educational settings should have access to all appropriate clinical and medical assessments/services, from the point of referral or diagnosis, to meet their needs;
7. that the Health Board ASD specific service teams devise the statutory Child and Family Support Plan for the person with an ASD and his/her family;
8. that automatic entitlement to a medical card should follow diagnosis of an ASD;

Practice

9. that information on treatment options and medical advice be made available to parents by relevant professionals; and that such information and advice reflect international standards of good practice and be adequate to enable parents to make informed choices about how to proceed on accessing the support they require, or which has been recommended, for their children;
10. that respite care (and, in exceptional circumstances for those who require it, residential care) be provided for families as their need arises, and that such respite and residential care be characterised by well-planned and structured, high quality, age and autistic disorder and AS/HFA differentiated programmes and activities.

CHAPTER 12: EDUCATION FOR TEACHERS, OTHER PROFESSIONALS AND SUPPORT STAFF

The Task Force recommends:

Teacher Education Policy

- 1. that personnel working in early education with children with ASDs be trained in appropriate interventions for children of this age, whether in pre-school provision provided under the aegis of the Department of Education and Science, of the Department of Health and Children, in private Montessori or other pre-schools, or in community playgroups;**
- 2. that the Department of Education and Science assume full responsibility for the provision of funded in-career development of teachers of pupils with ASDs to ensure that all such teachers are proficient in the teaching of the requisite developmental skills and in the formulation and evaluation of Individualised Education Programmes (IEPs); that training be provided in the implementation of specific approaches to the teaching of pupils with ASDs such as Applied Behaviour Analysis (ABA), TEACCH, the Hanen Communication System, the Picture Exchange Communication System (PECS) and other emerging strategies; that differentiated training for teachers working with Asperger's Syndrome be provided; that the proposed Visiting Teachers be educated about ASDs, and that they are skilled in the use of a range of ASD specific interventions before taking up an appointment; that all teachers undertaking in-career recognised courses in special education, including education on ASDs, have financial support from the Department of Education and Science;**
- 3. that the proposed Special Needs Organisers in regional centres assume a central responsibility for organising in-career training of teachers of pupils with ASDs at regional level; that a hierarchically sequenced menu be provided, to guide teachers so that they receive the minimum basic information and skills first, and then move on to progressively important topics of training; that the minimum knowledge base prior to assignment to a special class or child be designated, and a timetable for working through the menu be established;**
- 2. that the Department of Education and Science ensure that adequate educational resources are provided both to teachers and to schools to meet the special educational needs of pupils with ASDs and to**

facilitate the implementation of specific approaches to the teaching of such pupils.

3. that induction courses which incorporate training in specific approaches to the teaching of pupils with ASDs be made available to all teachers assuming a post as a teacher of pupils with ASDs for the first time; that the proposed the Special Needs Organisers play a role in organising these courses at regional level;
4. that the Department of Education and Science, in conjunction with the National Educational Psychological Services (NEPS), formulate guidelines for teachers of pupils with ASDs on appropriate responses to challenging behaviours; that these guidelines be implemented uniformly in all schools enrolling pupils with ASDs.
5. that the Department of Education and Science encourage teachers and other personnel engaged in the education of pupils with ASDs in the furtherance of their knowledge and expertise by providing funding for further study and research in this area;
6. that research be conducted on the optimal educational interventions for pupils with AS/HFA; that the Research and Development Committee of the Department of Education and Science prioritise, and provide significant funding for, research on classroom practice and the outcomes of different intervention strategies with children with ASDs at all levels of the education system;
7. that all ASD education and training courses be periodically evaluated and that, in its review and promotion functions, the Teaching Council have particular regard to the education and training of teachers in relation to ASDs;

Teacher Education Practice

8. that training in Special Needs Education be an integral part of the basic training of all teachers; that modules on AS/HFA be included in pre- and in-service teacher training for primary and second level teachers;
9. that expertise in the empirically validated approaches be available within the schools in each geographical region;
10. that teachers of pupils with ASDs, including teachers in special pre-school classes, have the opportunity to attend funded in-service

courses in the education of children with ASDs on at least an annual basis;

- 11. that teachers of pupils with ASDs be specifically and adequately trained in the management of challenging behaviours on the part of pupils with ASDs, with particular emphasis on the use of non-aversive techniques in responding to such behaviours;**

Other Professional and Support Staff Policy

- 12. that training for Health Board psychologists include ASD-specific training, and that in-career training be provided for serving Health Board psychologists;**
- 13. that the Universities be funded to develop or expand their clinical training programmes to include ASD training, at the undergraduate and post-graduate levels; that all clinicians be versed in the various major approaches to educating persons with an ASD;**
- 14. that funding by the Department of Education and Science, via the Higher Education Authority, be targeted to support professional programmes in educational psychology, and that such programmes include ASD-specific training, in order to meet the needs of children and families with ASDs and other special educational needs;**
- 15. that funding be increased and targeted, via the Higher Education Authority, for the education of increased numbers of speech and language therapists, occupational therapists and behaviour specialists and pending the education of adequate numbers that such personnel be recruited internationally;**
- 16. that a National Forum be established to facilitate communication between teachers and other personnel who are working in the field of ASDs;**

Other Professional and Support Staff Practice

17. that all professionals and working with persons with ASDs, should receive on-going training in the distinctive disorders on the autistic spectrum, in general ASD issues, and in the specific disciplines as related to ASDs;
18. that programmes specific to the disorders in the autistic spectrum be established to qualify persons as classroom assistants in colleges and post-secondary training institutions; that there be access to funding for further education and development for classroom assistants; that accredited training courses be established for classroom assistants forming an accreditation ladder leading to career progression;
19. that all staff working with children and families with ASDs receive ASD specific training; that specialised training be given to educators, parents, siblings and home helps to maximise communicative environments for children, and to reinforce programmes being delivered by the schools, and this training be delivered by personnel with expertise in ASDs.

CHAPTER 13: IMPLEMENTATION STRUCTURES

The Task Force recommends:

Policy

1. that an Inter-Departmental ASD Working Group, with parental representation, be established as a sub-committee of the existing Inter-Departmental Co-ordinating Committee between the Departments of Education and Science and Health and Children; that its general remit include the production of a Service Level Agreement to indicate clearly the responsibility, including resources, of each Department, to secure and to implement educational provision and support services for persons with ASDs; that the recommendation in Chapter 15 of this Report - that the announced inter-Departmental team of high-level officials to co-ordinate response to the needs of children with autism be established and that it co-ordinate responses to the needs of all children with an ASD; and that it be given responsibility for overseeing the implementation of the recommendations of this Report – be implemented;
2. that at regional level a Regional Autistic Spectrum Disorder Educational Planning and Advisory Service, with parental representation, be created, under the joint authority of the

Department of Education and Science and the National Council for Special Education, administered and managed by a Regional Special Needs Organiser, and supported by a multi-assessment planning team, to identify and secure effective provision for children with ASDs within a Statutory Statement of Educational Need; that this Regional Autistic Spectrum Disorder Educational Planning and Advisory Service be established within each Health Board region, and work in formal collaboration with the Health Board ASD Intervention Services facilitated by the Health Board ASD Co-ordinator, so as to ensure the automatic delivery of the necessary support services;

- 3. that, as an interim measure, and until such times as independent diagnostic services, as recommended by the Task Force, have been agreed and implemented, the current Health Board arrangements (including whatever ASD Services are available, facilitated by the newly established post-holders for ASD co-ordination within the Health Boards) convey the details of the ASD diagnosis, and the impact of the diagnosis on the child's or young person's ability to learn and to socialise, in order to assist the Department of Education and Science Inspector, and the multi-disciplinary team to identify appropriate interventions and supports for persons diagnosed with an ASD;**
- 4. The Task Force recommend that the Department of Education and Science establish an Independent Review Body, with parental representation, in keeping with the Report of the Planning Group: A National Support Service for Special Education for Students with Disabilities (2000) recommendations, to intervene in cases when provision is disputed; that the appeals system endorse mediation as the preferred method of resolving disagreement or disputes between parents and statutory bodies; that, in the event of an appeal of a draft statement of need based on the multi-disciplinary assessment, the child remain in an interim placement pending the outcome of the appeal; that the model adopted by the Department of Education and Science be accessible, independent and speedy, operating within the maximum time frames recommended in this Report; that the members of the Appeals Board be independent and have expertise in ASD appropriate education;**
- 5. that Statementing procedures have an in-built review process;**
- 6. that administrative, co-ordinating and funding arrangements be established by the Department of Education and Science, in collaboration with the Departments of Enterprise, Trade and Employment and the Department of Health and Children, to provide for the proposed structures for the implementation of educational**

provision, training and supported employment, and support systems, for persons with ASDs proposed in this Report;

- 7. that Primary, Second level and Post- second level Curriculum Working Parties be established to make detailed recommendation on the curricular/vocational content and strategies to enable teachers and others to meet effectively the needs of pupils attending primary and secondary, including special, schools and continuing education colleges or training facilities;**
- 8. that the Department of Education and Science establish, through its Inspectorate Services, a system to evaluate ASD provision;**
- 9. that the In-Career Development Unit of the Department of Education and Science establish a working party to initiate and support the expansion further of localised/accredited training for ASDs; that the In-Career Development Unit, and relevant courses in universities, be resourced to provide the appropriate education and training programmes to enable staff to meet the educational needs of persons with ASDs;**
- 10. that the Department of Education and Science take overall responsibility for early and pre-school education for children with ASDs; that a separate Post-Primary Special Education Section be established within the Department; that a Disabilities Civil Rights Section be established within the Department of Education and Science with overall responsibility for policy formulation in relation to educational rights for people with disabilities; that Regional Resource Centres be established in the offices of the Special Needs Officers, to equip parents with the means by which they can make the best use of the system of rights provided for by the Act proposed in Chapter 14; that additional staff be recruited for the Department of Education and Science Special Education Sections and for the new agencies as soon as possible, and trained as appropriate;**
- 11. that estimates to address the predicted increase in incidence, and the recommendations for educational provision and support services for persons with ASDs, contained in this Report are fully costed and included in the annual budgetary allocations for the Department of Education and Science (and for other Departments of state providing support services), with effect from the next financial year.**

CHAPTER 14: EDUCATION FOR CHILDREN WITH AN ASD – CONSTITUTIONAL AND LEGISLATIVE ISSUES

The Task force recommends:

Policy

1. that urgent attention be paid by the Government to the need for appropriate constitutional reform to provide clearer provision for the rights of persons with disabilities to education and to provide a more solid legal basis for advanced legislation in the field; that the constitutional right to education be viewed against the over-arching right to equality; that the right to equality be considerably strengthened; that the constitutional right to education be reformulated to concentrate more on the substantive right itself; that the main emphasis in any reformulated right be the right to an *equally effective* education for all, regardless of difference; that the basic right at stake be ‘basic learning’ for all, which includes adults;

2. that a civil rights statute dealing with the educational rights of persons with disabilities be enacted; that this statute set out substantive and procedural rights; that the practical proposals for such a civil rights statute made by the National Disability Authority inform the content of such a statute; that this statute be clearly premised on the philosophy of a right to an equally effective education; that among other things the statute contain
 - a clear and strong statutory presumption in favour of the mainstream,
 - a statutory guarantee that no person with an ASD should be excluded from a school or other service for any reason arising as a consequence of his/her disability,
 - a statutory statement of educational need, and a statutory child and family support plan, in respect of each individual,
 - a process whereby an annual *Individual Education Plan* could be identified and a ‘contract’ signed *well before* each school year involving the parents, the school, the child and other relevant independent professionals,
 - a statement of resources to be dedicated to this end (dedicated and put in place *well before* the commencement of the school year),
 - a genuinely tailored curriculum with a prior statement of testing modalities that makes sense for the person,
 - a statutory right to related professional and other services to enable the person take advantage of his/her educational opportunities,

- a statutory right to appropriate on-going education and training, according to need, for adults with disabilities (including ASDs),
- a method of evaluation of progress,
- a statutory right to a place in a school that is reasonably proximate in geographic terms
- an independent appeals/complaints mechanism in which differences between parents and educational and service providers can be speedily resolved without recourse to the courts;

that the title of the statute clearly reflect the movement to a civil rights-based philosophy and should therefore be entitled *Individuals with Disabilities Education Act -Ireland (IDEA-I)*; that, in addition to providing for substantive and procedural rights such a statute establish an independent monitoring body for the civil rights of persons with disabilities in education; that, under the proposed *IDEA-I*, a Disabilities Civil Rights Section be established within the Department of Education with overall responsibility for policy formulation in relation to educational rights for people with disabilities; that Regional Resource Centres be established under the *IDEA-I* to equip parents with the means by which they can make the best use of the system of rights provided for by the Act;

3. that the proposed Disabilities (Education and Training) Bill make legal provision for the kinds of positive action that will be required to make the educational rights of persons with disabilities a reality; that the education section of the Disabilities Bill could be incorporated into the primary civil rights statute or it could stand alone - either way that it complement the civil rights of persons with disabilities to education;
4. that specific provision be made in the forthcoming *Official Languages Equality Bill* in respect of the right of persons with an ASD whose first or family language is Irish, to have access to assessment, education and support services through the medium of Irish;
5. that the Department of Education and Science prepare and update regularly a user-friendly guideline handbook regarding the responsibilities, procedures and practices involved in the provision of the right to suitable education for persons with disabilities, including those with autistic spectrum disorders, and dealing also with the implementation of the legislative provisions outlined above.

CHAPTER 15: POLICY

The Task Force recommends:

Policy

1. that the constitutional and statutory rights of children with autistic spectrum disorders and items a-n listed in paragraph 15.2.6 above, be addressed as a matter of urgency in educational policy;
2. that, as announced by the Minister in October 2000, an inter-Departmental team of high-level officials to co-ordinate response to the needs of children with autism be established; that it co-ordinate responses to the needs of all children with an ASD; and that it be given responsibility for overseeing the implementation of the recommendations of this Report;
3. that a report describing existing services and outlining progress in the implementation of policy in respect of special education services, including identification and assessment, for persons with disabilities be published on the web-site of the Department of Education and Science, and updated on a twice yearly basis; that it have particular regard to the provisions of the Constitution and of statute law and, in relation to the education of persons with an ASD, to the seven guiding policy principles adopted in January 2000 by the then Minister as a basis for the service (see par. 5.1.8), the recommendations of the *Task Force on Autism* as contained in this Report and the outcome during the previous six months of any legal proceedings regarding educational provision for persons with an ASD;
4. that the database project “*to identify special needs of pupils and support the development and implementation of policy*” as announced by the Minister on 9.3.2000 be proceeded with as a matter of urgency, that it be compatible with WHO systems, e.g. WHODAS II, that it be updated annually and appropriately co-ordinated with similar initiatives in other Government Departments and State agencies;
5. that the improvements to the education service for children with autism announced in October 2000 be implemented in respect of all children with an autistic spectrum disorder;
6. that the definition of "Autistic Spectrum Disorders" currently used by the Department of Education and Science (par. 5.1.2) be updated to read as follows:

A suitably qualified professional or professionals will have assessed and diagnosed such students as having an autistic disorder, childhood autism, pervasive

developmental disorder- not otherwise specified or Asperger's Syndrome, according to the criteria of DSM-IV-TR, ICD-10 or an equivalent diagnostic system.

7. that key stakeholders, and parents in particular, be consulted in the development of educational policy in respect of children with an ASD.

CHAPTER 16: COSTS AND BENEFITS OF EDUCATIONAL INTERVENTION FOR PERSONS WITH AN ASD

The Task Force recommends:

Policy

1. that priority be given to resourcing and implementing the educational services for people with ASDs, from the point of diagnosis, so that the long-term consequences of the investment in these people may accrue to their personal development and equality of status in Irish society; that funding be forthcoming to provide the specialist resources and equipment necessary to meet the needs of all children/students with an ASD, so that their individual interests and strengths can be maximised.
2. that the needs of persons with an ASD be met as a matter of constitutional priority and savings, if necessary, be made elsewhere; that the costs associated with meeting the needs of persons with autistic spectrum disorders be faced by society and by the administrators of the education system; that where services are contracted out by the State to third party organisations, the State provide the funds necessary to meet its constitutional obligations; that where responsibilities shift from one Department to another there be a commensurate movement of resources from one Department to another; that there be close co-ordination between Departments in the delivery of services;
3. that current inequities in provision, which arise primarily by virtue of the quantity and quality of provision in the area of residence of the person with an ASD, be addressed and guidelines for provision issued to the two major Departments of State with obligations to provide services to persons with ASDs – i.e. to the Departments of Health and Children and Education and Science;

4. **that funding be made available, through the Departments of Education and Science, Enterprise Trade and Employment, and Health and Children, to ensure that the gains of education are built upon through continuing education and supported employment initiatives;**

Practice

5. **that research be conducted in Ireland into the costs and benefits of early and on-going educational intervention for persons with ASDs.**