

Researching Parents Experiences of the ASD Diagnostic Process in County Mayo.

04/10/2007

Fionnuala Langford, Philippa Brooks, Amanda Byrne, Sinead Carthy, Breda Garvey-Cecchetti, Olive Laundon, Clare O' Shaughnessy

S.L.T Research Group, S.L.T Department, Primary, Community and Continuing Care, H.S.E West, Co. Mayo. S.L.T Department, N.U.I Galway.

ACKNOWLEDGEMENTS

This study was supported by a National Disability Authority Research Promotion Scheme Award 2006. We also wish to acknowledge the HSE West and National University College Galway for their support of the project.

We are grateful to our research assistant, Geraldine Mills, Speech and Language Therapist, for her very thorough analysis of the data.

Finally we would like to acknowledge our gratitude to the parents who participated in the study, without whom this would not have been possible.

Please note: The views and opinions contained in this report are those of the authors and do not necessarily reflect the views or opinions of the N.D.A.

TABLE OF CONTENTS.

Executive Summary	4
1 AIMS OF THE STUDY.	6
2. LITERATURE REVIEW.	7
Prevalence	8
Diagnostic Practice	9
Assessment of ASD	10
Age at diagnosis	11
Reaction to Diagnosis	12
Satisfaction with Diagnosis	12
Disclosure Interview	15
Legislation in Ireland	16
ASD Diagnostic Service in Mayo	16
3. METHODOLOGY	17
Ethical Approval	17
Management of Upset	18
Sampling and Take up	18
Researchers	19
Tools Used	19
4 DATA ANALYSIS	21
5 FINDINGS	22
Diagnostic Process	22
Day of Diagnosis	24
Suggestions for Improvements to Services	27
Satisfaction with Service	29
6. DISCUSSION	30
7. RECOMMENDATIONS	34
8. LIMITATIONS	34
9 CONCLUSIONS	35
10 BIBLIOGRAPHY	36
11. APPENDIX	41

EXECUTIVE SUMMARY

This study, which was funded by the National Disability Authority (NDA) Research Promotion Scheme in 2006, was undertaken by a group of speech and language therapists working in Primary, Community and Continuing Care, HSE (Health Service Executive) in Co Mayo. The aims were to extend a study undertaken previously which examined professionals views of the local diagnostic service for Autism Spectrum Disorder (ASD). The present study elicited parents views of the service. Recent studies on this topic were consulted as were documents on autism produced in Ireland over the last ten years. Criterion sampling was employed and the data generated was analysed using a mix of grounded theory, thematic content analysis and framework analysis.

A focus group was followed by semi structured individual interviews which were later transcribed and analysed by a research assistant. The questions in the focus group were selected based on our previous study and the literature review. The questions used in the semi structured interviews were based on the analysis of the focus group data. The same questions were used in each individual interview.

Four main themes emerged. These were

- Diagnostic Process
- Day of Diagnosis
- Suggestions for improvements to services
- Satisfaction with Service

Several sub-themes within each main theme were identified and examined.

The time taken to diagnose autism spectrum disorder (ASD) for our participants ranged from 4 months to two and a half years. The average age at time of diagnosis was three years seven months. 80% of our participants were satisfied with the diagnostic process; these results compare favourably with recent studies in UK and Canada. They are due in part to local initiatives in Co Mayo, including being diagnosed at Primary Care level rather than a secondary or tertiary level, the availability of an expert panel to discuss diagnosis of complex cases, being prioritised by the professionals, accurate diagnoses and joint working.

There was some dissatisfaction also with the service and reasons cited include location of disclosure interview, lack of information received, lack of support following the diagnosis, the perceived disjointed nature of services resulting in delays and criticism of the autism forum.

Suggestions from parents included a Public Health Nurse (PHN) and general Practitioner GP screening service, more Speech and Language Therapists (SLT) and Psychologists, Applied Behaviour Analysis (ABA) schools, support including counselling, more sharing of information and being given the diagnosis in their own homes.

RECOMMENDATIONS

We would support the recommendation by parents that screening for ASD should occur at developmental check ups. This would involve training of Public Health Nurses and GPs in recognising symptoms of this complex condition and using screening checklists.

We would further recommend the following:

1. Information packs on Autism Spectrum Disorder (ASD), including local support networks should be collated and made available to professionals involved in the diagnosis of Autism Spectrum Disorder, to give to parents at the disclosure interview.
2. Best practice guidelines for informing parents of their child's disability, as being prepared by the National Federation of Voluntary Bodies, should be drafted and adopted in the region.
3. Parents should be kept informed and involved at every level of the process.
4. Support services need to be developed for parents following diagnosis, including the availability of counselling.
5. The delay in accessing intervention services should be eliminated by the Primary Care service continuing to provide a service to the child until the intervention service by the Voluntary Organisation begins and time frames for provision of these services be adhered to.

AIMS OF THE STUDY

To extend the research undertaken by the ASD Research group in 2005, which examined professionals views of ASD diagnostic practice in Co Mayo.

To explore parents perceptions and experiences of this service

To inform policies and procedures in this area. This is particularly relevant at this time as community services are moving towards a more integrated model of service delivery for children aged 0-6 years with a disability.

To examine considerations raised by parents in undertaking this research.

LITERATURE REVIEW

The term “autism” was first used by a pioneer in the field of childhood psychiatry in the US in the 1930s, Leo Kanner, to describe a condition he had witnessed in a number of children referred for assessment. Kanner defined this condition as including a profound autistic withdrawal, an obsessive desire for sameness and a good rote memory. The children he diagnosed also had mutism, or used language without communicative intent and were over sensitive to stimuli. Work on classifying these and similar clinical phenomena continued in the decades following Kanner’s work. (Anthony (1958a,b,1962), Kolvin (1971) and Rutter (1972) . It was noted that his definition described only a portion of the children presenting with related symptomatology. It is as a result of the narrowness of Kanner’s definition that Wing and Gould developed their hypotheses of a spectrum of autistic conditions. Wing and Gould conducted a study of the prevalence of autism in the Camberwell area of London in the late seventies .(Wing & Gould 1979). They found that the abnormality of social interaction was closely related to the difficulties with communication and imagination and referred to this cluster of impairments as the “Triad of Impairments” (Wing 1998) They concluded that “There were no clear cut borderlines between typical autism, atypical autism, Asperger syndrome and other manifestations of the triad.” They proposed the hypotheses that there is a wide spectrum of autistic conditions and that typical autism was only a part thereof. Most authorities in the literature agree with Wing and Gould’s hypotheses, as Kabot, Masi and Segal report in their review of current literature (2003)

Baird, Cass and Slonims (2003) state that “autism is a behaviourally defined disorder, characterised by qualitative impairments in social communication, social interaction, and social imagination, with a restricted range of interests and often stereotyped repetitive behaviours and mannerisms” Kabot et al 2003 in a review of the literature report that authorities agree that autism can be defined at three interdependent levels

1. As a neurological disorder related to brain development
2. As a psychological disorder of cognitive, emotional and behavioural development

3. As a relationship disorder . Kusch & Petermann (1995) describe this as “a failure of normal socialization”

Many authorities also define autism as provided in the fourth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM- IV; American Psychiatric Association, 1994) According to the DSM-IV autistic disorder is one of several pervasive developmental disorders (PDDs) caused by a dysfunction of the central nervous system, which leads to disordered development in the child. The DSM-IV classification includes Rett's Syndrome, Childhood Disintegrative Disorder, Asperger's Disorder and Pervasive Developmental Disorder, not otherwise specified (PDD-NOS) The other internationally used system of diagnosis and classification is the International Classification of Diseases (ICD 10). The section on autistic disorder is very similar to the DSM-IV section. The ICD 10 also refers to the whole group of autistic disorders as “Pervasive Developmental Disorders” (PDD)

In this report the term autism spectrum disorders (ASD) (Wing 1988) will be used throughout. It should be considered interchangeable with the term pervasive developmental disorder as used in DSM-IV and ICD 10.

ASD is a lifelong developmental disability that affects the way a person communicates and interacts with people around them. Children and adults with ASD have difficulties with everyday social interaction. According to Wing (1998), “Everyone with the condition of ASD shares a difficulty in making sense of the world. Their ability to develop friendships is generally limited, as is their capacity to understand other people's emotional expression. “

Persons with ASD often have sensory differences. “A defect in the systems which process incoming sensory information causes the child to overreact to some stimuli and underreact to others. The child with ASD often withdraws from her environment and the people in it to block out an onslaught of incoming stimuli.” (Temple Grandin)

Prevalence

For many years the prevalence of ASD was considered to be 4 - 5 per 10,000 births (Wing & Gould 1979). Recent studies however have found that the overall rate of Autism Spectrum Disorders may be as high as between 40 to 60 per 10,000. (Baird, Charman et al 2000, Chakrabarti & Fombonne 2001.) Baird, Cass & Slonims (2003) agree that prevalence is approximately 5-6 per 1000 in younger children, an estimate used by the National Initiative for ASD Screening and Assessment (NIASA) in the

National Autism Plan for Children (NAPC) in UK (2003), as a basis for planning services. As most studies of prevalence are on young children, prevalence in adolescents or adults may be different.

Bristol et al 1996 found that pervasive developmental disorders (PDDs) are more common in childhood than cancer, Down's syndrome or cystic fibrosis.

It has been found that the number of children with ASD is increasing (Fombonne 2003). Studies have found several factors which account for this increase, including the increasing recognition that individuals with average IQ may have an ASD (Gilbert & Wing 1999), changes in diagnostic practices, and the inclusion of individuals with comorbid conditions such as Tuberous sclerosis, Down's syndrome (Howlin, Wing & Gould 1995), and Tourette syndrome (Baron-Cohen et al 1999)

Regression in ASD

In approximately 25 – 30 % of children with ASD significant regression or stasis of development is reported between 15 and 21 months of age. (Baird, Cass and Slonims 2003). In many such cases however it was found that subtle abnormalities in development of social communication were present before the onset of the reported regression.

Diagnostic Practice

In Ireland practice regarding the identification, referral, assessment and diagnosis of children on the autism spectrum varies throughout the country (Report of the Task Force on Autism 2001) The Health Services Executive has responsibility for the provision of assessment and diagnostic services for persons with ASD. According to the Task Force Report the structure through which this is done can vary, from Community Services, Regional Diagnostic and Assessment Services for ASDs, Learning Disability Services, to Child and Adolescent Mental Health Services. "There is currently no comprehensive identification system operational and there is no AS/HFA (Asperger syndrome/ High Functioning Autism) database or specific designated service provider." Report of Task Force on Autism(2001.)

Recent legislation however, (The Disability Act 2005) has led to the setting up on a national basis of Early Intervention Teams (also called Disability Teams), for children with disabilities "who will provide assessment, diagnosis and intervention to all children within the target group from a defined geographical area" (HSE Discussion

Document Draft 2007). These teams will assess, diagnose and provide intervention for all children with a disability including physical and learning disability as well as those with ASD. The Task Force on Autism (2001), recommends the “Health Board Regional Diagnostic and Assessment ASD specific diagnostic team model”. This would allow team members to develop expertise specifically in the area of ASD. In the UK, the National Autism Plan for children (NAPC) (Le Couteur, National Autistic Society 2003) was adopted as the framework for services. This recognised the barriers to early diagnosis of ASD, including separate waiting lists for each professional group. It reports that each local area in the UK has a child development service though there is great variety of models of service organisation. The NAPC recommends an identification of needs, including a diagnosis where appropriate and an individual action plan to meet those needs. This will involve a Multi Agency Assessment within a timeframe of 30 weeks from referral to the child development service to completion of the assessments. According to Hodge (2005), in the US eligibility for services is dependent on receiving a label of the presenting condition, including ASD. Parents attend with their child for assessment and parent interviews. In many areas results of these investigations are evaluated by an Assessment Panel and a diagnosis is given to parents before they leave the clinic

Assessment of ASD

Due to the variability in the nature and development of ASD in different children, diagnosis of the condition, especially in younger children may be complex . Siklos & Kerns (2007) refer to the scarcity of assessment measures suitable for use with preschool age children. Kabot, Masi & Segal 2003 list a range of assessments to screen for ASD in children, including *The Checklist for Autism in Infants and Toddlers (CHAT)* (Baron-Cohen et al 1992), *The Pervasive Developmental Disorder Screening Test 11 (PDDST 11)* (Siegel 1999), *The Screening Tool for Autism in Two-Year-Olds (STAT)* (Stone & Ousley 1997). Authorities recommend that if a child fails the screening test, a formal diagnostic evaluation should be completed. (NAPC 2003, Filipek et al 2000) . A more recent test to screen referred children is the *Modified CHAT* (Robins, Fein, Barton & Green, 2001)

Other instruments have been devised for more in-depth investigation of autistic behaviour including *The Autism Diagnostic Interview – Revised (ADI-R)* (Lord, Rutter & Le Couteur 1994), *The Childhood Autism Rating Scale (CARS)*. Schopler et

al 1980), *The Gilliam Autistic Rating Scale (GARS)* (Gilliam 1995), *The Gilliam Aspergers Disorder Scale (GADS)* (Gilliam 2001), *The Autism Diagnostic Observation Schedule (ADOS)* (Lord et al 1994). NAPC also refers to *The Diagnostic Interview for Social and Communication Disorders (DISCO)* (Leekham et al 2002) Experts recommend that no single assessment instrument be used as the sole basis for diagnosing autism. (Kobot et al 2003) The NAPC (2003) in the UK recommends that the assessment be carried out by a multi-agency assessment team, that all members of the team have specific ASD training and that at least one member be trained in either the ADI-R or the DISCO.

The team should include a psychologist, speech and language therapist, community paediatrician and a child and adolescent psychiatrist. Other assessments should also be available e.g. occupational therapy, physiotherapy and dietetic if necessary. The Task Force on Autism (2001) recommends “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”. The Task Force also recommends that “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” as in Rutter et al 1999 and Filipek et al (2000) The Task Force report also points to the fact that some children’s presentation makes it difficult to make a definitive diagnosis without a prolonged period of observation during which assessment is continued. This should not preclude their eligibility for specialised services available to children with a diagnosed ASD, according to the Task Force.

Age at diagnosis

Advances in diagnostic techniques means that symptoms of ASD can be detected in children as young as 12-18 months of age (Baghdadli, Picot, Pascal, Pry, & Aussilloux, 2003; Dawson & Munson, 2002), and can be reliably diagnosed by the age of 30 months (Gillberg, Norden & Ehlers, 1996). Baird (2002) reports that a reliable diagnosis of autism can be made at between 2 and 3 years of age, but that a diagnosis of the broader autism spectrum is less reliable at this young age. Retrospective studies reviewing videotapes of children with ASD at their first

birthday correctly identified 10 of 11 children with ASD and 10 of 11 typically developing children. (Osterling & Dawson 1994) In reality however early identification is rarely the case. According to international literature the majority of parents do not receive a diagnosis until the child is between 5 and 6 years of age (Howlin & Asgharian, 1999, Howlin & Moore, 1997, Siklos & Kerns 2007). The Murray ERHA (2000) study in Ireland found that 87% of parents of children with ASD reported their concerns about developmental delays at a very early stage. By the time their children reached four years of age 56% had still not received a definitive diagnosis of their child's condition.

The Report of the Task Force (2001) found that many parents were given reassurances from health professionals that their pre-school child was fine, only to find later that their fears were well founded.

The report states "Parents may be further blocked in their efforts to secure a clear diagnosis where they were 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."

Reactions to the diagnosis

A review of the ASD diagnostic literature yields a large quantity of information ranging from records of personal experience (Sullivan, 1997), clinical observations (Siegel, 1997) and parents reactions to the diagnosis (Howlin & Moore 1997, Midence & O'Neill, 1999, Siklos & Kerns 2007,). For some parents who have had early suspicions that their child may have an ASD, relief may be the overwhelming emotion that some one else has finally corroborated their concerns (Midence & O'Neill, 1999, Sullivan 1997). Other parents may experience shock and confusion and refuse to accept the diagnosis (Siegel, 1997). For others, grief and loss for the "hoped for" child can be the principal reaction (Midence & O'Neill, 1999). For the majority of parents, they can experience each of these emotions at different stages of the diagnostic process. A recurring theme emerging from the literature is the need to support and possibly counsel parents and families at this time which currently rarely is on offer to parents. (Siklos & Kerns 2007)

Satisfaction with the diagnostic process

There have been several international studies to explore parents experiences of and satisfaction with the diagnostic process. (Howlin & Moore 1997, Howlin & Asgharian, 1999, Siklos & Kerns 2007). The heterogeneous nature of this complex disorder as well as the inconsistencies vis a vis, assessment methods, diagnostic criteria and speed and accuracy of diagnosis cited in the literature means that parents experiences of and reactions to the diagnostic process can vary considerably.

Brogan & Knussen (2003) investigated parent satisfaction with the disclosure of the diagnosis in a sample of 126 Scottish parents. They highlight two main reasons why ensuring parental satisfaction with the diagnostic process can be such a difficult task.

- 1) The age at diagnosis (Howlin & Asgharian, 1999, Howlin & Moore, 1997)
Parents can be faced with a stressful wait of on average 2-4 years for a diagnosis and such delays in disclosure have been positively correlated with parent dissatisfaction (Baird et al 2000, Howlin & Moore, 1997. A recent review of current practice in Chesterfield Royal Hospital in UK arose out of a 2003 recommendation by the NAPC (2003) that a child should complete an assessment process from referral to completion of assessment within 30 weeks. The review, carried out by Preece and Mott in 2006 found that it was not possible to complete all assessments within this timeframe and that a more reasonable expectation is to complete all ASD assessments within 52 weeks. In a survey of professionals experience of the diagnostic practice in County Mayo in 2005, 50% of respondents reported completion of assessment within 26 weeks (Brooks et al 2007)
- 2) Many parents are faced with vague and tentative diagnoses. Howlin & Moore (1997) and Quine & Pahl (1987) have reported that parent satisfaction is greater when a definite diagnosis can be given. This is in line with submissions to the Task Force on ASD, which found parental frustration with inaccurate or piecemeal diagnoses. In many submissions to the Task Force (2001), professionals have diagnosed children as having “autistic like” features. Other children, later diagnosed with ASD received diagnoses of Expressive- Receptive/ Semantic Pragmatic Language Disorder from a Speech and Language Therapist.

A positive experience within the diagnostic process has a significant impact on a parent's initial reaction to the diagnosis of a developmental disability (Cottrell & Summers 1990, Leff & Walizer, 1992). Goin-Kochel, Mackintosh & Myers (2006) however, in an aptly titled study "How many Doctors does it take to make an ASD spectrum diagnosis?" surveyed 494 parents to determine their level of satisfaction with the process of getting an ASD diagnosis. 40% were "not satisfied" with the process. A large scale study of 1200 parental reports by Howlin & Moore 1997 and Howlin & Asgharian (1999) found that 49% of families in the UK were either "not very" or "not at all" satisfied with the diagnostic process.

They reported that over a quarter of parents waited in excess of 5 years before a diagnosis was confirmed. The two main factors relating to parent satisfaction were receiving an early diagnosis and receiving a definite diagnosis (ASD vs presenting symptoms). Parents whose children received earlier diagnoses, visited fewer professionals and received more clear-cut diagnoses such as ASD vs "Autistic Features" reported greater satisfaction. It was also indicated that the more professionals that families saw enroute to the diagnosis, the more negatively parents viewed the experience. Parents reported visiting on average between 4 & 5 clinicians before receiving a diagnosis. The report of the Task Force on ASD 2001 reported parents difficulties with fragmented assessments, with different professionals writing separate reports and in many submissions leading to delays in diagnosis, misdiagnosis as referred to earlier or, in some cases no diagnosis at all. Baird et al (2003) report that parents want "the streamlining by multi-agency agreement of assessment processes to ensure that children are not subjected to repeat assessments and families are not asked to repeat the same emotionally difficult information"

Siklos & Kerns (2007) in the most recent study on this subject corroborate the findings of earlier studies. In a study of 56 parents in Canada replicating the Howlin & Moore study (1997) over 50% were dissatisfied with the diagnostic process. They identified a relationship between the specific type of autistic features of the child and the diagnostic experiences of the family. They found that parents of children with

greater communication impairments were more likely to report decreased stress levels surrounding the diagnosis, increased satisfaction with the diagnostic process and increased satisfaction with services received since diagnosis. Siklos & Kerns (2007) proposed 3 main reasons to explain this finding. Firstly the communication impairment may have been a clear indicator for the parents that something was seriously wrong with their child and the diagnosis may not have come as such a surprise. Secondly these parents may have had an easier time getting their child diagnosed because the communication impairment would have been picked up at an earlier age.

Siklos & Kerns make the point that it is easier to diagnose communication impairments than impairments in behaviour or social relating. Psychologists and speech and language therapists have standardised tests to measure communication skills in young children. Social and behavioural difficulties however are less easy to measure using standardised instruments and may not be as apparent in a clinical setting. The third finding, relating to increased satisfaction with services post diagnosis, suggests those children with communication impairments may be receiving more services than children with greater behavioural or social features of ASD.

Disclosure Interview

Brogan & Knussen (2003) found that 55% were satisfied with the disclosure interview. Interestingly factors most highly related to parent satisfaction were, the manner of the professional, the quality of the information given including the provision of written information and time allocated to asking questions. The satisfied parents also reported that their suspicions had been accepted by the professionals. Baird et al (2000) found that parental acceptance of the diagnosis was maximised by “the content and manner of the professionals involved, in particular the warmth, honesty and an openness about what is definitely known as well as areas of uncertainty”. They also found that “Involvement of both parents and where possible a member of the continuing care team has been shown to be related to greater acceptance”. The Western Health Board’s Strategic Plan for Intellectual Disability and Autism (2004) recommended that parents be given an information pack on diagnosis and also that a regional website be developed which would display this information. Carson (1995) makes specific recommendations regarding the disclosure

of a diagnosis to parents including that they be told in a private setting and that they be offered a second meeting with the professional giving the diagnosis.

Legislation in Ireland

The Disability Act 2005 Part 11, recently come into law in Ireland, deals with assessment of need and service statements. If an assessment confirms a disability the assessment report will include a statement of the nature and extent of the disability, the education and health needs which arise as a result of it and the services considered appropriate to meet the persons needs.

According to the draft discussion on the proposal for the development of a national framework, the assessment, diagnosis and intervention will be carried out by the Early Intervention Teams referred to earlier. This act aims to prevent in the future some of the difficulties experienced by the parents who made submissions to the Task Force in 2001.

ASD Diagnostic Service in Mayo

This study in County Mayo endeavours to evaluate the experiences of parents of children with ASD with the diagnostic process they have undergone. Primary Community & continuing Care personnel of the HSE provide the ASD diagnostic service in Mayo, usually speech and language therapists and psychologists in conjunction with the consultant paediatricians from Acute Hospital Care. Complex cases may be referred to the Autism Forum for discussion and to reach a diagnosis. The forum consists of clinicians experienced in the area of ASD. It is multi agency, made up of a psychologist, paediatrician, speech and language therapist and psychiatrist from PCCC, Child and Adolescent Mental Health and Acute Hospital Care. The professionals who have completed assessments present their findings and usually a video of the child. The case is discussed and a diagnosis reached where possible. Parents of the child do not attend the autism forum. Feedback to the parents is made by the professionals who have carried out the assessments.

At present there is no multidisciplinary or specialist team of professionals in the county with responsibility for diagnosing ASD, although professionals involved do work as closely together as is practicable. Change in this regard is due imminently, as

Early Intervention Teams, as referred to, are set up. Recruitment for personnel is underway.

METHODOLOGY

This research project is qualitative in design and nature. Qualitative research methods allow a researcher to work with raw data, to explore the nature of the stories people tell or the way they behave (Carter Y. & Thomas C 1997). It allows one to look at different perspectives, understanding and interpretations that people bring to certain situations. We chose to engage in qualitative research as by its nature it is unstructured, needing the flexibility and adaptability of the researcher to respond to the information received rather than impose a structure upon it. In both the collection and analysis of qualitative data, the researcher is the primary instrument.

We analysed the raw data from the individual interviews by adopting an eclectic mixture of approaches, rather than adhering to strict Grounded Theory methodology.

We had planned to base the project on a Grounded Theory Approach. This approach, which was developed by Glaser & Strauss (1967) is defined as an overall approach to research and a set of procedures for developing theory through the analysis of data. (Punch 1998). This allowed us to use information gained early on to further explore the research topic. Theory emerges by comparing the data from one interview to the next interview by further exploring the themes emerging. This is how we analysed the raw data from the Focus Group Interview. This data was used to plan the semi-structured interviews, which followed. In our case, due to unforeseen difficulties in acquiring the services of a research assistant to transcribe the individual interviews. it was not possible to conduct the note taking, coding, memoing, and sorting in the manner prescribed. Thematic Content analysis and Framework analysis were used instead.

Ethical Approval

Ethical approval was sought prior to participants being recruited in December 2006. As there is at present no Ethics Committee for the HSE this matter was discussed at length with the Research Project Manager of HSE West. Approval was received from the HSE West Regional Manager for the project.

In February 2007 the project was submitted to the newly formed Ethics Committee in NDA for approval on a pilot basis.

Management of Upset

A counsellor was contracted and available to participants during and after the Focus Group Interview and following individual interviews. In the event this service was not utilised.

Sampling and take up

“A sample is a finite part of a statistical population whose properties are studied to gain information” (Webster 1985). We engaged in a form of purposeful sampling called criterion sampling. In criterion sampling all cases that meet the criteria are used. This method of sampling is high in quality assurance.

In our case the criteria we set was all parents of children, who had attended the Speech and Language Therapy department and were diagnosed with A.S.D, from January 2005 to January 2007. Children who were diagnosed with A.S.D who did not have speech and language therapy input in the diagnosis were not included. This criterion sample group covered a range of ages, severity of disorders, social class and included both genders.

In January 2007 an Information sheet and Cover Letter were sent to every potential participant. These were carefully prepared to ensure that study participants had sufficient information about the study in which they were being invited to participate to make a fully informed and free decision about whether or not to participate as recommended in the University of Waterloo Office of Research Ethics Guidelines.

An information letter was also sent to every professional currently involved in ASD services in Mayo. This list included Speech and Language Therapists, Psychologists, Paediatricians, Child Psychiatrists, Child and Adolescent Mental Health Nurses and In Home Managers. Professionals in both HSE and the local Voluntary Organisation, which provides ASD Services, were informed.

Five parents spontaneously contacted our department after the initial letter volunteering to participate in the research. The parents from whom there was no response one week after the deadline of 6th February were contacted by telephone by a department secretary. Following this second contact, five additional parents agreed to

participate. Four parents elected to attend a Focus Group and six opted for a semi structured individual interview.

One focus group was held, attended by two people. We had originally planned to have two focus groups in two different locations but due to lack of participants this was reduced to one. Two parents did not attend the focus group as one parent forgot and the other had an ill child. These two parents were included in our individual semi-structured interviews. Therefore we had two people in our focus group and eight semi-structured interviews. Our overall take up was 40%.

Researchers

The Focus Group was facilitated by an experienced Speech and Language Therapy lecturer. The Semi Structured Interviews were conducted by a Senior Speech and Language Therapist working in Community Services.

Both researchers meet the criteria set out by the National Disability Authority Guidelines for Research for Children with Disabilities (NDA 2002)

Tools Used

Two means of obtaining raw data were used.

Focus group:

“Focus groups are a form of group interview that capitalises on communication between research participants in order to generate data” – Kitzinger J & Barbour (1999). The idea behind the focus group method of obtaining data is that being in a group can help people explore and clarify their views in ways that would be less accessible in a one to one interview. The focus group attempts to recreate a natural phenomenon i.e., a group of people with something in common discussing an issue. A facilitator leads the discussion.

In our case an individual who has no connections with the Speech and Language Therapy Department facilitated the Focus Group Interview. This facilitator is an experienced researcher and lecturer from the SLT Department of National University of Ireland, Galway. No other Speech and Language Therapist was present to avoid any barrier to participants speaking openly about the service they had received.

Before the focus group commenced, the parents in the group completed a written questionnaire. The questionnaire was designed to allow us to gain a profile of their

child regarding their age, services they had received and their child's diagnosis. A consent form, agreeing to involvement and to audio taping of the interview was signed by each parent prior to the focus group. They were reassured of confidentiality.

The focus group took place in a local hotel with refreshments available. A clerical officer was contracted to transcribe the interview, which was also audiotaped.

A set of questions, which were informed by our literature review were prepared prior to the Focus Group. These followed the guidelines set down by Stewart and Shamdasani (1990) and Kreuger (1988)

The raw data obtained from the focus group identified emerging themes and was used to formulate questions for the semi-structured interviews which followed.

Semi-structured interviews.

In semi-structured interviews respondents are asked to tell their own story within the confines of the research topic (Carter Y & Thomas C 1997).

We chose this method of collecting data as we felt it would allow the subject matter to be discussed in some depth revealing the nature of parent's experience, feelings and perceptions.

The researcher attended the homes of the parents in question. Once again consent forms were given to the parents prior to the semi-structured interviews. They were informed that the interviews would be taped (with their consent) and later transcribed verbatim.

All parents consented to have the interviews taped.

The same set of questions was used in each interview.

A mother and a father attended the Focus Group.

Seven mothers attended individual interviews. In the eighth interview both parents attended.

The children involved included eight boys and two girls.

Current Ages of the children ranged from 3 years to 10 ½ years

The time since diagnosis ranged from four months to two years

Diagnosis' included 6 reports of Autistic Spectrum Disorder, 2 Asperger's Syndrome, 1 High Functioning ASD, and 1 Mildly Autistic.

Two children attend pre/playschools. One attends a crèche. Six attend Mainstream Primary Schools. One attends a home based programme.

Data Analysis

The Focus Group Interview and each individual interview were recorded. The focus Group interview was transcribed by a clerical officer who was present, whereas the individual interviews were transcribed verbatim later by a contracted Research Assistant.

Each of the 6 members of the ASD Research Group and the research assistant analysed and coded these transcripts independently. This involved a combination of Thematic Content Analysis and Framework Analysis. Thematic Content Analysis allowed us to identify and categorise the recurrent and common themes. By incorporating Framework Analysis we ensured that the integrity of individual respondents' accounts were preserved throughout the analysis.

The five key stages outlined in framework analysis are: familiarisation; identifying a thematic framework; indexing; charting; mapping and interpretation. Framework analysis while using a thematic approach, allows themes to develop both from the research questions and from the narratives of research participants (Rabiee, 2004).

The first step in the analysis of the present data was familiarisation with the data.

During this process the major themes began to emerge. The next stage involved identifying a thematic framework, by writing memos in the margins of the texts in the form of short phrases, ideas, and concepts, arising from the texts and beginning to develop categories. The third stage, indexing, involved the application of codes to the whole data set in a systematic way. The fourth stage, charting, included rearranging the data according to the thematic content. These charts contained only summaries of the data, so the researcher could see across cases and under themes the range of data. The fifth step, mapping and interpretation, involved the use of diagrams to physically explore the relationships between the concepts. The findings of the analysis are presented below.

FINDINGS

Following the analysis procedure previously outlined four main themes emerged:

- Diagnostic process
- Day of diagnosis
- Suggestions for improvements to services
- Satisfaction with service

Each of the main themes will be discussed in turn and illustrated by quotation, to substantiate the meaning inherent in each.

Diagnostic Process

There were a number of sub-themes within this main theme: the first person respondents' mentioned concerns to; length of the diagnostic process; onward referral; first mention of ASD; ASD Forum; and difficulties experienced by the child.

The respondents spoke about the first person they mentioned their concerns to. Six participants spoke initially to their Public Health Nurse (PHN).

In six of the cases the Public Health Nurse referred children to speech and language therapy.

Participants reported varying timeframes when speaking about length of the diagnostic process. Length of diagnostic process ranged from four months to two and a half years.

"...about four or five months...but I was seeing somebody constantly...I was seeing the psychologist or the speech therapist or whatever constantly over those four or five months..."

(Interview Eight)

"...so maybe about ten months from the health nurse to the diagnosis..."

(Interview Seven)

"...just over four months...which seemingly is very quick..."

(Interview Four)

"...it was about two and a half years of a gap..."

(Interview Two)

Respondents reported a number of onward referrals during the diagnostic process, for example being referred to the psychology department by the speech and language therapist.

Four parents spoke of the speech and language therapist noticing that something was not right and seeking permission to refer on to another professional.

“...we then had him seen by the developmental doctor here and she referred him onto the psychologist...”

(Interview Four)

“...so when I went in with him first (to speech and language therapy) he was all over the place he wouldn't sit down he wouldn't do anything she asked him to do...and the tantrums she noticed the tantrums...and she said to me, “If he was my child I'd get him assessed”, so it was her that put me in contact with X (psychologist)...”

(Interview One)

Parents' experiences of the first mention of ASD varied both in terms of the person who mentioned ASD and the feelings that ensued.

“...in psychology...oh I hated it the first day yeah it was an awful shock...even though I knew deep down something wasn't right it was the shock of it...”

(Interview Seven)

“...I think X (speech and language therapist) definitely mentioned it.....we didn't know a thing about ASD, to be quite honest I thought ASD was physically deformed kids...”

(Interview Six)

“...so I just asked her (psychologist) “are you going down the lines of ASD with X?” and I 'd say she wouldn't have told me there and then I honestly don't think she would have said it the week before Christmas I'd say they would have dragged it out until after Christmas but I asked myself...”

(Interview Five)

“...she (psychologist) came here to see myself and Y (husband) and she mentioned that she thought he might be autistic...and that was a big shock to us because we just really didn't see that coming at all...”

(Interview Three)

A number of participants spoke about their child's diagnosis being discussed at the ASD forum

“They are a faceless group” (Focus Group. Parent A)

I've never seen the ASD board”(Focus Group. Parent A)

During the interviews respondents spoke about the difficulties experienced by their children that led to a diagnosis of ASD spectrum disorder (ASD).

“...it’s something for a child not to talk but a child not to even acknowledge that there was other people there...”

(Interview Five)

“...he asked me was he mixing with other children and I said no...and another thing we noticed about him too if there was any other kids here he never wanted to play with them...just couldn’t take loud noise...”

(Interview One)

“...he was just uncontrollable he was like a wild animal absolutely crazy...he took an awful long time to potty train...he took off all his clothes and ran through it...”

(Interview Six)

Day of diagnosis

The following four sub-themes were identified under the above main theme: setting diagnosis was given in; delivery of diagnosis; information given; and feelings surrounding diagnosis.

Participants reported being given the diagnosis in a variety of settings. For two participants it occurred over the telephone. For others the diagnosis was given in a clinic room. The number of people present at the delivery of the diagnosis also differed among respondents. In two cases, there was one health professional and one parent present, while in other cases a number of health professionals and both parents were present.

“...we got a the phone call wasn’t it and then we got a written report after that...”

(Interview Six)

“...there was myself and my husband and there was the team of doctors there was four of them...”

(Interview One)

“...because another day we went up they had a team up there. There was about four there...the following day it was X (psychologist) on her own...”

(Interview Five)

“...X (psychologist) rang me because I knew the autistic forum was on that morning and herself and Y (speech and language therapist) were going to it...and then she rang me when it was over...”

(Interview Three)

While seven of respondents reported being happy with the delivery of the diagnosis, it emerged that two parents were not happy with the manner in which they were given the diagnosis for their child.

“...well there wasn't really any other way she could have told me she could have waited to come down from X maybe and called here to see me but she had told me the forum was on in X...so I was sitting by the phone like pure anxious waiting for the call from her like I mean I wouldn't have appreciated waiting three hours for her to come down I wanted to know what the story was so that was best way she could have told me...”

(Interview Three)

“...she came back and said “well you know what you were thinking it might be well it is”, that was it it ...was just like that and they walked out the door and I just bawled into tears it was just so cold and I mean I suppose there's no easy way to say it but there was no support absolutely...”

(Interview Four)

“...very sensitive very understanding...didn't rush us out the door...I did feel very comfortable and I felt as if anything was wrong or if I had more questions I had no problems going back...”

(Interview Seven)

“...they came out to talk to us to see how we felt after the thing and of course I was in tears all over the place and they explained to us then what would happen...”

(Interview Six)

“...I thought it was fine...explained the assessments...and the conclusion was ASD and what that was about...”

(Interview Eight)

There were differing reports from participants regarding information given from health professionals. Six parents felt they received enough information about ASD spectrum disorder while four felt that they did not receive any information.

“...I felt I had loads of support and I had loads of information and anytime I needed information I got it...and I got extra stuff from the internet and I got a book and I was provided with all this information...”

(Interview Eight)

“...when we were asking for more informationgave us photocopied information and gave us pointers on books or pieces to read I think they even gave us websites to look up...”

(Interview Six)

“...no, got none...I mean you go to the library and you get the books and you do it yourself...”

(Interview Five)

“...what questions do you ask when you’re told your child’s been diagnosed as being autistic...we weren’t fit to ask questions and then they weren’t there to ask questions to because it wasn’t their problem anymore...”

(Interview Four)

“...I went on the internet myself...X (psychologist) was very good...she answered any questions we had and she gave us every information she could...”

(Interview Three)

“They didn’t give me any information”

(Focus Group Parent B)

“ I had to self teach myself everything.....anything I know and what I have done with x(child’s name) I have learned from books and the internet”

(Focus Group Parent B)

Participants reported a number of feelings surrounding the diagnosis of ASD spectrum disorder. These included: shock; grief; and relief. Participants also spoke of the stress caused by the diagnosis and of ASD taking over their lives and their homes.

“...huge shock because I didn’t see it...”

(Interview Three)

“...I remember feeling oh there’s a rock in my chest I remember feeling the thing going up my spine and a lump in my throat...”

“...I felt well that’s that sorted now I can talk about it now I can talk about my daughter now it’s not as if she’s a thing anymore or there’s something wrong with her I have a name for it now...and it’s been clarified and I can talk about it now...”

(Interview Two)

“...it has taken over our lives...”

(Interview Four)

“...I know I cried but it was a relief and a shock and the whole lot together...”

(Interview Five)

“...I was upset and shocked like you know worried about his future...”

(Interview One)

“...ASD took over there for a while...”

(Interview Six)

“...I was fine and I knew then I was going I knew I was probably going to get some help with him so that was great to know you know because it was getting really frustrating trying to you know handle him and not know what I was doing so I thought that’s great that’s a relief I’m going to actually get some help maybe now...I was relieved yeah I was really relieved...”

(Interview Eight)

Suggestions for improvements to services

Within this main theme a number of sub-themes emerged: support during and after diagnosis; services and resources; waiting lists and length of process; information giving.

Throughout the data there was the sense of a need for increased support both during and after the diagnosis. A gap in support between diagnosis and being seen by X (Voluntary Organisation) was repeatedly highlighted by participants. It was felt that having a counsellor assigned to a family during and after diagnosis would be most appropriate.

“...I think there’s a time there when you’re definitely left on your own...you’d need somebody maybe you’d nearly need a counsellor...I think between there’s a time between ye and X (Voluntary Organisation) when you’re on your own and I think the time you need somebody to come out to you or maybe just to keep in contact you know...”

(Interview Seven)

“...you shouldn’t be on your own...”

(Interview Two)

“There is a lot of fear, especially when the support isn’t coming.....you don’t know what’s going to happen, there’s no one calling out or making a phonecall. You’re on your own”

(Focus Group. Parent A)

“The onus is too much pushed on parents.....not enough support after diagnosis”

(Focus Group. Parent A)

It emerged from the data that services and resources need to be improved according to the participants. One parent suggested setting up ABA schools and home programmes. One other parent suggested that a Public Health Nurse screening service should be put in place.

“...set up ABA schools around the country have intense speech therapy...everything just intervention, intervention and intense intervention...but the services are dire they’re dire...”

(Interview Four)

“...I think kids in general should be given more checks by a health nurse...I think each year is a milestone in a child’s life and a lot can happen and I do think definitely that if there was more checks a health nurse would probably pick up on things that we mightn’t even notice...”

(Interview Six)

Waiting lists and the length of the diagnostic process were highlighted as needing improvement by respondents.

“...you don’t have enough psychologists or you don’t have enough speech therapists...”

(Interview Eight)

“...ten months it’s a long time to be left wondering what is going on or what is wrong with your child...the waiting lists are there...it’s obvious the resources are stretched to the limit and it doesn’t matter how high on the list you are...”

(Interview Six)

“...the waiting list is the big thing...”

(Interview Three)

There was also a sense throughout the data that there is a need for more sharing of information between professionals and parents.

“...maybe GPs should be putting up a little more information about this sort of thing...”

“...or maybe we can have a role there in informing the GPs of how to do it..”

“...exactly yeah because that’s kind of the first place you go to your GP...”

(Interview Eight)

“...if a child is diagnosed with ASD they should be given a list of things that they can do, who they can contact, list of websites, information...”

(Interview Four)

“...if you could have some access maybe I don’t know through playschools or the only thing I felt was that my playschool could have got back to me a bit more and said that they never really gave me any comeback...they just says “yeah he was a bit disruptive”...”

(Interview Three)

Participants reported dissatisfaction with the setting of the delivery of the diagnosis. It emerged that parents would prefer to be told in their own homes rather than in a clinic. It was also felt that parents should be invited to the ASD forum.

“...what I’d prefer now is if they knew I think they should actually go to someone’s house...that was a hard walk now out from that door out to the front door of the clinic...”

(Interview Five)

“...I think it might be a good idea if the parents were invited to the forum of their own kids...you know just to see how did they come up with these things...what are their opinions...”

(Interview Six)

Satisfaction with service

Three sub-themes arose under this main theme: two parents were very satisfied with the service; one parent was very satisfied with professionals involved but felt the service was disjointed; four parents were satisfied with the service; and one parent was dissatisfied with service.

“...we were very satisfied...I felt everyone explained everything very well...”

(Interview Seven)

“...I’m very satisfied...I can’t complain at all about it...”

(Interview Eight)

“...well all the professionals...I have to admit I’m very satisfied with them...I really think there should be more coordination between the HSE and the Department of Education...”

(Interview Three)

“...I’d be satisfied yeah...”

(Interview One)

“...I was satisfied that everything was being done...it wasn’t just one or two as I said it was several visits we had I couldn’t count how many visits we had...”

(Interview Two)

“...well I can’t say we were satisfied...I would say we were dissatisfied...”

DISCUSSION

This study in Co Mayo revealed that the time taken to diagnose ASD for each of the participants ranged from 4 months to two and half years. Previous studies (Howlin & Moore, 1997, Baird et al 2000) found that parents waited 2 – 4 years for a diagnosis. According to international literature the majority of parents do not receive the diagnosis until the child is between 5 and 6 years of age (Howlin & Asgharian 1999. Howlin & Moore 1997. Siklos & Kerns 2007). This study found that the average age at time of diagnosis was 3 years 7 months.

The satisfaction level of parents with the diagnostic process is 80% and as such is well above satisfaction levels in previous studies. Eg Siklos and Kerns 2007 reported satisfaction level of 49 % and Howlin and Moore found that 51% of the parents they studied were satisfied with the diagnostic service they received.

We believe the high satisfaction levels were due to the following;

- diagnosis at Primary Care level,
- the provision of the Autism Forum,
- prioritisation among professionals of children with a query ASD,
- monthly Paediatric Autism Clinic,
- joint working between professionals
- accurate diagnoses.

At present children in Mayo with a suspected ASD are assessed by professionals at Primary, Community and Continuing Care level. When they receive a diagnosis of ASD they are then referred to a separate and dedicated autism service provided by a local voluntary organisation. This is in line with the recommendation by the Task Force on Autism (2001) that “the assessment and service provision functions be independent of each other”.

Following from the Disability Act (2005), it is proposed in the HSE discussion document (2007) that “Early Intervention Teams (Disability Teams) will provide assessment, diagnosis and intervention to all children within the target group” This target group may include all children with a disability, not just children with ASD. Assessment by a team, as opposed to professionals from separate disciplines, should

move closer to Baird et al's (2003) parental recommendations which were to avoid the repetition of emotionally difficult information.

The existence of the Autism Forum facilitates the diagnosis of complex cases has meant that delays are minimised. Members of the Autism Forum have developed expertise in diagnosing autism. The Autism Forum is in line with the Assessment Panels in the US as reported by Hodge (2005)

Children with a query Autism Spectrum Disorder are presently prioritised among professionals in Primary, Community and Continuing Care (PCCC) While, as yet there is not a formal pathway of care for these children, professionals generally see these children for a diagnostic work – up as a matter of priority. They are not put on a general waiting list for further assessment

The local Paediatric Department now conducts a monthly Autism Assessment Clinic. A recent development in Co Mayo is the introduction of a monthly case led multidisciplinary meeting. This joint working will continue as the Disability teams, proposed in the HSE discussion document, develop.

Our study has revealed that the parents attended an average of three professionals prior to the diagnosis of an ASD. Siklos and Kerns found that children attended an average of 4.6 professionals. Howlin and Moore (1997) and Gohen – Kochel et al (2006) found a negative correlation between numbers of professionals seen and their satisfaction with the diagnostic process.

9 out of our 10 participants received a definite diagnosis and one parent received a tentative diagnosis. This parent also expressed dissatisfaction with the diagnostic process. This is in line with the findings of Howlin & Moore (1997), Quine & Pahl (1987)

Despite the high level of satisfaction expressed by our participants, the experiences of our parents were not always positive.

The reasons cited include;

- location of disclosure interview,

- lack of information received,
- lack of support following the diagnosis,
- the perceived disjointed nature of services resulting in delays,
- criticism of the autism forum.

In our study the participants reported receiving the diagnosis in a number of settings, including over the phone, in a clinical setting and at home. Carson (1995), in his best practice guidelines advises that parents receiving any disclosures about their child of a sensitive nature be told together in a “private and comfortable place without any interruptions”. There was also inconsistency regarding information received with 40% of our participants being dissatisfied. Charman & Baird (2002), recommend that both parents be involved at the disclosure interview and where possible a member of the continuing care team. In no case in our study was a member of this team present. The NAPC (2003) specifies that there should be two professionals from the assessment team present at the diagnostic disclosure. This has not been the experience of many of our participants. One participant highlighted lack of access to the assessment team following diagnosis when questions arose. Carson (1995) recommends a follow up meeting after parents have had time to digest the diagnosis given. There was some criticism of the long waiting lists for separate professionals prior to the diagnosis. This was also found by the NAPC (2003). The majority reported lack of support following diagnosis, especially as there is a waiting period between the diagnosis being disclosed and intervention services commencing. We believe that if best practice guidelines, as suggested by Carson (1995) and the NAPC (2003) were in place, the experiences of lack of information and lack of immediate support for families could be avoided. Best practice guidelines for informing parents of their child's disability in Ireland are at present being prepared by the National Federation of Voluntary Bodies.

The NAPC recommend giving parents a standard information pack including local information. The Western Health Board (2004) also recommends an information pack and development of a website displaying the information. This is supported by Siklos & Kerns (2007), who also recommend counselling for parents at this time.

In reference to the autism forum 40% of the participants received their diagnosis in this way. The forum was considered a very positive and efficient way of

diagnosing complex cases of ASD by professionals (Brooks et al 2007) and this type of diagnostic panel is common practice according to Hodge (2005). However, parents expressed concerns that they did not know what professionals were at the forum and were not invited to participate. We know from previous studies that parental satisfaction with the diagnostic process is positively correlated with experiences of being involved and informed within the process Siklos & Kearns (2007). This has also been highlighted by Hodge (2005) who stated that parental involvement in the process of reaching a diagnosis is crucial if parents are not to feel cast to one side while others reach conclusions about their child.

The autism forum may therefore need to be reviewed to allow for greater parental involvement.

Some suggestions from parents on improving the diagnostic service were

- A Public Health Nurse and G.P screening service,
- More speech and language therapists and psychologists,
- Applied Behaviour Analysis (ABA) schools,
- Support including counselling,
- More sharing of information
- Being given the diagnosis in their own homes.

Training in the use of screening tools is one of the recommendations in the Report of the Task Force (2001) and the NAPC (2003).

RECOMMENDATIONS

We would support the recommendation by parents that screening for ASD should occur at developmental check ups. This would involve training of Public Health Nurses and GPs in recognising symptoms of this complex condition and using screening checklists.

We would also recommend the following:

1. Information packs on Autism Spectrum Disorders (ASD), including local support networks, should be collated and made available to professionals involved in the diagnosis of ASD, to give to parents at the disclosure interview.
2. Best practice guidelines for the disclosure interview should be drafted and adopted in the region.
3. Parents should be kept informed and involved at every level of the process.
4. Support services need to be developed for parents following diagnosis, including the availability of counselling.
5. The delay in accessing intervention services should be eliminated by the Primary Care service continuing to provide a service to the child until the intervention service By the Voluntary Organisation begins and time frames for provision of these services be adhered to.

Limitations:

While our main findings are supported by other research, it must be borne in mind that this is a small scale project and the sample was restricted in number. Therefore it is important to be cautious in generalising the findings.

The lack of take up of the invitation to participate necessitated further contact with potential participants, which risked biasing results. This risk was minimised by the secretary, rather than the researcher, making contact.

The limited attendance at the focus group was unexpected and unavoidable and may have affected the range of raw data obtained.

We had difficulties contracting a research assistant following the withdrawal at short notice of the contracted individual. This delayed the immediate transcription of interviews.

The children of all the participants in our study had communication impairments and had attended speech and language therapy. This fact may have created a possible bias because studies have shown that parents of children with communication impairments are generally more satisfied with the diagnostic process.

CONCLUSION

This study has several clinical implications for professionals working in ASD diagnosis. As a direct result of the study we aim to introduce information packs to all SLT's working in ASD diagnosis in Co. Mayo. We also aim to draft best practice guidelines for the disclosure interview. Copies of this report will be made available to all stakeholders.

As the Disability Act comes into force it will be interesting to replicate this study when the Early Intervention Teams are established to evaluate its impact on parental satisfaction.

BIBLIOGRAPHY

1. American Psychiatric Association (1994) Diagnostic and Statistical Manual of Mental Disorders 4th Edn (DSM 1V) Washington, DC: American Psychiatric association
2. Anthony, E.J. “An experimental approach to the psychopathology of childhood autism.” *British Journal of Medical Psychology*, 1958, 21, 211-225.
(a)
3. Anthony, E.J. “An etiological approach to the diagnosis of psychosis in childhood” *revue de Psychiatrie Infantile*, 1958, 25, 89-96, (b)
4. Baghdadli,A.,Picot,MM.C.,Pascal,C.,Pry,R.,& Aussilloux, C. (2003). Relationship between age of recognition of first disturbances and severity in young children with ASD. *European Child & Adolescent Psychiatry*, 12, 122-127.
5. Baird G, Cass H and Slonims V. (2003) “Clinical Review. Diagnosis of Autism” *British Medical Journal*. Vol 327 Aug 2003 488 - 493
6. Baird G., Charman T., Cox A. Baron – Cohen S. Swettenham J. Wheelright S. & Drew A. (2000) “A screening instrument for autism at 18 months of age: A six year follow up study.” *Journal of the American Academy of Child and Adolescent Psychiatry*, 39 694 - 702
7. Baird, G., McConachie, H. & Scutton, D. (2000) Parents Perceptions of Disclosure of the Diagnosis of Cerebral Palsy. *Archives of Disease in Childhood* 83:475-80
8. Baron-Cohen S., Allen J., & Gillberg C. (1992) “ Can autism be detected at 18 months? The needle,the haystack, and the CHAT” *British Journal of Psychiatry*, 161, 839-843
9. Baron-Cohen S., Scahill V.L., Izaguirre D., Hornsey H. & Robertson MM> (1999) “The prevalence of Gilles de la Tourette syndrome in children and adolescents with autism: A large scale study.” *Psychological Medicine*, 29, 1151-1159
10. Bristol M. Cohen D.J. Costelloe E.J. Denckla M. Eckberg T.J. Kallen R. et al (1996) “State of the science in autism; Report to the National Institute of Health. *Journal of Autism and Developmental Disorders* 26, 121-154

11. Brogan, Clare, A., Knussen, Christina (2003). The Disclosure of a Diagnosis of an autistic spectrum disorder. *ASD*. Vol 7 (1)31-46
12. Brooks P., Byrne A., Carthy S., Garvey-Cecchetti B., Langford F. & Laundon O. (2007) "Diagnosing Autism Spectrum Disorders" *Bulletin. RCSLT* Oct 2007 666, 20-22
13. Carson S. "We need to talk" *LLAIS* 38 Autumn 1995
14. Carter Y. & Thomas C. (1997)"Research Methods in Primary Care" *radcliffe Medical Press: Oxa UK*
15. Chakrabarti S. & Fombonne E. (2001) "Pervasive Developmental disorders in preschool children" *Journal of the American Medical Association*, 285, 3093-3099
16. Chapter 4 "Identification, Referral and Initial Assessment" *The Report of the Task Force on Autism 2001.*
17. Cottrell, D., J., & Summers, K. (1990). Communicating an Evolutionary diagnosis of disability to parents. *Child*,16, 211-218
18. *Disability Act (2005) Part 11. No 14 of 2005. The Oireachtais*
19. *Discussion Document Draft (2007) "Proposal for the Development of a National Framework for Service Delivery for Children 0 – 5 with Complex Developmental Needs" Health Service Executive*
20. Ehlers, S., Gillbeg, C. & Wing, L. (1999). A screening questionnaire for Asperger syndrome and other high functioning ASD spectrum disorders in school age children. *Journal of ASD and Developmental Disorders*, 29, 129-141
21. FombonneF "The prevalence of autism" *Journal of the American Medical Association* 2003 289 87-89
22. Gillberg C. & Wing L (1999) "Autism: Not an extremely rare disorder" *Acta. Psychiatrica Scandanavia*, 99 399-406
23. Gillberg, C., Nordin, V., & Ehlers, S., (1996). Early Detection of ASD: Diagnostic Instruments for CliniciN. *European Child and Adolescent Psychiatry*, 567-74.
24. Gilliam J.E. (2001) "Gilliam Asperger's Disorder Scale" *austin TX: Pro-Ed*
25. GilliamJ.E.(1995) "Gilliam Autism Rating Scale" *austin, TX: Pro-Ed*

26. Glaser B & Strauss A: (1967) "The discovery of grounded theory" Chicago, Aldine
27. Gohen-Kochel, R. Macintosh, V.H. Myers, B, J., (2006) How Many Doctors Does It Take To Make An ASD Spectrum Diagnosis? ASD 10 (5) 439-451
28. Grandin Temple "Emergence. Labelled Autistic" 1986 Future Horizons
29. Hodge (2005) "Reflections on Diagnosing Autism"
30. Howlin, P., & Moore, A. (1997). Diagnosis in ASD: A survey of over 1200 patients in the UK. ASD, 1, 135-162.
31. Howlin, P., & Asgharian, A (1999). The Diagnosis of ASD and Asperger Syndrome: Findings from a survey of 770 families. Developmental Medicine and Child Neurology, 41, 834-839.
32. Howlin P. Wing L. & Gould J. (1995) "The recognition of autism in children with Down syndrome: Implications for intervention and some speculations about pathology" developmental medicine and Child Neurology, 37, 406-414
33. Kabot S, Masi W. and Segal M "Advances in the Diagnosis and Treatment of Autism Spectrum Disorders" Professional Psychology; Research and Practice 2003, Vol 34, No 1, 26 – 33
34. Kitzinger J. & Barbour R.S. "Introduction: The challenge and promise of focus groups" In (Eds) Barbour R.J. & Kitzinger J. "Developing focus group research: Politics, Theory and Practice" (pp1-20) London: Sage
35. Kolvin, I. "Studies in the childhood psychoses.i. Diagnostic criteria and classification" British Journal of Psychiatry, 1971, 118, 381-384
36. Kreuger R.A. (1998) "Focus Groups: A Practical Guide for applied research" London: Sage
37. Le Couteur A. (Chair) 2003 "National Autism Plan for Children" National Autistic Society
38. Leekham (2002) "The Diagnostic Interview for Social and Communication Disorders" (DISCO)
39. Leff P.T. & Walizer E. H. (1992) "The uncommon wisdom of parents at the moment of diagnosis" Family Systems Medicine, 10, 147-168
40. Lord C. Rutter M. & Le Couteur A (1994) Autism Diagnostic Interview Revised. A revised version of a diagnostic interview for caregivers of

41. Lord C. Rutter M. (1994) "Autism Diagnostic Observation Schedule"
42. Mansell, W., Morris, K. (2004). A Survey of Parents Reactions to the diagnosis of an autistic spectrum disorder by a local service. *ASD*. Vol 8(4) 387-407
43. Midence, K. & O'Neill, M. (1999). "The Experience of Parents in the Diagnosis of ASD: A Pilot Study", *ASD* 3:273-85
44. National ASD Plan for Children (NAPC) (2003) "Plan for the identification, assessment, diagnosis and access to early intervention for preschool and primary school aged children with ASD spectrum disorders" National Autistic Society 2003
45. National Disability Authority (2002) "Ethics in disability research"
46. Osterling J., & Dawson G. (1994). "Early Recognition of children with autism: A study of first birthday home videotapes." *Journal of Autism and Developmental Disorders*, 24. 247-257
47. Preece & Mott. (2006) "Multidisciplinary Assessment at a Child Development Centre: Do we conform to Recommended Standards" *Child Care Health Development* 2006 Sept; 32 (5): 559-63
48. Punch K.F. (1998) "Introduction to social research. Quantitative and qualitative approaches" London: Sage
49. Quine, L. & Pahl, J. (1987). First Diagnosis of Severe Mental Handicap: A study of Parental Reaction. *Developmental Medicine and Child Neurology* 29: 232-242
50. Rabiee F. (2004) "Focus group interview and data analysis." *Proceedings of the Nutrition Society*. 63 655-660
51. Robins D.L., Fein D., Barton M.L. & Green J.A. (2001). "The Modified-Checklist for Autism in Toddlers; An initial study investigating the early detection of autism and pervasive developmental disorders." *Journal of Autism and Developmental Disorders*, 31, 131-144
52. Rutter, M "Childhood schizophrenia reconsidered" *Journal of Autism and Childhood Schizophrenia*, 1972, 2, 315-3337.

53. Schopler E., Reichler R.J., DeVellis R.F., & Daly K. (1980) "Toward objective Classification of childhood autism: Childhood Autism Rating Scale (CARS).
Journal of Autism and Developmental Disorders, 10. 91-103
54. Siegal B. (1999) "Pervasive Developmental Disorder Screening Test 11" San Francisco; University of San Francisco, Langley Porter Psychiatric Institute, Pervasive Developmental Disorder Laboratory and Clinic
55. Siegel, B. (1996) *The World of The Autistic Child: Understanding and Treating Autistic Spectrum Disorders*. New York NY: Oxford University Press
56. Siklos, Susan. Kerns, Kimberly A (2007). Assessing the diagnostic experiences of a small sample of parents of children with ASD spectrum disorders. *Research In Developmental Disabilities* 28, 9-22.
57. Stewart D.W. & Shamdasani P.N. (1990) "Focus Groups: Theory and Practice" London: Sage
58. Stone W.I., & Ousley O.Y. (1997) "STAT Manual: Screening Tool for Autism in Two-Year-Olds 2 Unpublished Manuscript, Vanderbilt University
59. Sullivan, R.C. (1997) "Diagnosis ASD: You Can Handle It", in D.J. Cohen & F.R. Volkmar (Eds) *Handbook of ASD and Pervasive Developmental Disorder*, pp 1007-20. New York: Wiley
60. Webster M. (1985) "Webster ninth new collegiate dictionary" Meriam-Webster Inc
61. Wing and Gould J. (1979) "Severe Impairments of social interaction and associated abnormalities in children; epidemiology and classification" *Journal of Autism and Developmental Disorders* 9, 11- 29
62. Wing L. "Classification and Diagnosis – looking at the complexities involved" *Communication*. Winter 1998. National Autistic Society.
63. World Health Organisation (1993) "Mental Disorders: A Glossary and Guide to their Classification in accordance with the 10th revision of the International Classification of Diseases: Research Diagnostic Criteria (ICD 10) Geneva: WHO

APPENDIX

CONTENTS

Page 42: LETTER TO PARENTS

Page 43: INFORMATION SHEET FOR PARENTS

Page 45: FOCUS GROUP QUESTIONNAIRE

Page 46: CONSENT FORM. FOCUS GROUP

Page 47: CONSENT FORM. INDIVIDUAL INTERVIEW

Page 48: INFORMATION ON CHILDREN

Page 49: INDIVIDUAL INTERVIEW QUESTIONS

Page 50: INFORMATION FOR COLLEAGUES

LETTER TO PARENTS

AUTISM RESEARCH PROJECT PARENTS EVALUATION OF MAYO PCCC DIAGNOSTIC SERVICE

22/01/2007.

Dear Parents

I enclose some information about a research project we are undertaking in our department. The aim of the project is to improve our diagnostic services to children with autism spectrum disorder. In order to do this we need your views.

We are contacting parents of all children who were given a diagnosis of ASD within the last two years and who attended the Speech and Language Therapy Department.

All views will be presented anonymously.

If you would like to consider participating in this research, we have enclosed more details with this letter.

If you would prefer not to become involved please disregard this letter.

Thank you,

Yours Sincerely,

Fionnuala Langford

Senior SLT

Lead Researcher

INFORMATION
AUTISM RESEARCH PROJECT
PARENTS EVALUATION OF MAYO PCCC DIAGNOSTIC SERVICE

RESEARCHERS

Phillippa Brooks, Senior SLT
Amanda Byrne, SLT
Sinead Carthy, SLT
Breda Garvey- Cecchetti, SLT Manager
Fionnuala Langford, Senior SLT.
Olive Laundon. Senior SLT
Clare O Shaughnessy, Lecturer SLT Department, NUIG

22/01/2007.

The above therapists from the Speech and Language Therapy Department are conducting a research project on autism in association with the Speech and Language Therapy Department in National University Galway. This research is part funded by the National Disability Authority.

The aims of the research are to explore parents perceptions and experiences of the service which diagnoses autism spectrum disorder in County Mayo and to improve our way of working as a result of the information gathered.

One parent of each child is invited to participate.

Participation in this research is voluntary. If you decide not to become involved there will be no negative consequences for your child's service. Your involvement would entail attendance of one parent at a Focus Group in Castlebar or Ballina in February 2007, and /or one parent volunteering for an individual interview at your home with Fionnuala Langford, Lead Researcher. At the Focus Group a member of the University staff will explain the purpose of the research and will facilitate parents to speak of their experiences in having their child assessed and diagnosed with autism spectrum disorder. No member of the speech and language therapy department in Co Mayo will be present. The group will last for approximately 90 minutes.

The individual interview will last for approximately one hour and will involve a conversation regarding your personal experience of your child being assessed and

diagnosed with autism. You may decline to answer any of the interview questions if you so wish. Further, you may decide to withdraw from this research project at any time without any negative consequences by advising the researchers. With your written permission, the interview will be tape-recorded to facilitate collection of information and later transcribed for analysis. All information you provide is considered completely confidential and will adhere to legislation on data retention. Your name will not appear on any report that results from this project, however, with your permission, anonymous quotations may be used.

Data collected during this project will be retained for two years in a locked office in our department.

We hope to complete the research project by November 2007. After its completion all participants will be notified regarding its results. We will contact participants by letter containing a copy of the report. We will also meet with parents following completion of the project.

An honorarium of 20 Euros will be paid to each participant at the Focus Group and to each parent who volunteers to be interviewed, in appreciation.

I would like to assure you that this research project will adhere to the ethical guidelines laid down by the National Disability Authority (2005).

If one of you would like to participate in this project, or would like additional information to assist you in reaching a decision about participation, please contact Karen Masterson, SLT secretary at 094 9049007. You may also contact Fionnuala Langford directly at 094 9050107 or by email at fionnuala.langford@mailn.hse.ie

Please let us know by 6 February 2007

Thank you for taking the time to read this information.

QUESTIONNAIRE

15/02/2007.

Thank you for attending this Focus Group. We would appreciate if you would complete the following questionnaire.

1. What age is your child?

2. What diagnosis did you receive for your child's difficulties?

3. Does your child attend
Please tick
 Preschool
 Local Primary School
 Special school
 Secondary School

4. How long since your child was diagnosed with Autistic spectrum disorder/
Autism/ Aspergers Syndrome?

5. Please indicate with a tick which services your child attended before being
diagnosed with Autistic Spectrum Disorder/Autism/Aspergers Syndrome

 Speech and Language Therapy Dept
 Psychology Dept HSE
 Paediatric Department
 Child and Adolescent Mental Health
 National Educational Psychology Service (NEPS)
 Other

6. Please indicate which of the following applies to you. Please tick

 Very Satisfied with diagnostic service

 Satisfied

 Dissatisfied

 Very Dissatisfied

Thank you for completing this questionnaire. There is no need to sign it.

CONSENT FORM

I have read the information presented in the information letter about a study being conducted by the SLT Autism Research Group in conjunction with the SLT Department of NUI Galway. I have had the opportunity to ask questions related to the research and have received any additional details I wanted.

I understand that this group interview will be audiotaped to facilitate the collection of information with the understanding that all information which I provide will be held in confidence. I will not be identified in the report or any publication related to this research.

I understand that I may withdraw this consent at any time without penalty by advising the researcher.

Participant Name: _____

Participant Signature _____

Witness Name: _____

Witness Signature: _____

Date: _____

CONSENT FORM

I have read the information presented in the information letter about a study being conducted by the SLT Autism Research Group in conjunction with the SLT Department of NUI Galway. I have had the opportunity to ask questions related to the research and have received any additional details I wanted.

I understand that this interview will be audiotaped to facilitate the collection of information with the understanding that all information which I provide will be held in confidence. I will not be identified in the report or any publication related to this research.

I understand that I may withdraw this consent at any time without penalty by advising the researcher.

Participant Name: _____

Participant Signature _____

Witness Name: _____

Witness Signature: _____

Date: _____

QUESTIONNAIRE

15/02/2007.

Thank you for attending this Focus Group. We would appreciate if you would complete the following questionnaire.

7. What age is your child?

8. What diagnosis did you receive for your child's difficulties?

9. Does your child attend

Please tick

- Preschool
- Local Primary School
- Special school
- Secondary School

10. How long since your child was diagnosed with Autistic spectrum disorder/
Autism/ Aspergers Syndrome?

11. Please indicate with a tick which services your child attended before being
diagnosed with Autistic Spectrum Disorder/Autism/Aspergers Syndrome

- Speech and Language Therapy Dept
- Psychology Dept HSE
- Paediatric Department
- Child and Adolescent Mental Health
- National Educational Psychology Service (NEPS)
- Other

12. Please indicate which of the following applies to you. Please tick

Very Satisfied with diagnostic service

Satisfied

Dissatisfied

Very Dissatisfied

Thank you for completing this questionnaire. There is no need to sign it.

Interview	Respondent/s	Age of child		Diagnosis	School/Preschool
1	Mother	Boy 3½		Autistic Spectrum Disorder	Creche
2	Mother	Girl 6 years		Autistic Spectrum Disorder	Mainstream NS
3	Mother	Boy 6 years		Mildly Autistic	Mainstream NS
4	Mother	Boy 3 years		Autistic Spectrum Disorder	Home Programme
5	Mother	Boy 4 years		Autistic Spectrum Disorder	Playschool
6	Mother and Father	Boy 5 years 7 months		Autistic Spectrum Disorder	Mainstream NS
7	Mother	Boy 5½		Asperger Syndrome	Primary School
8	Mother	Boy 4 years		ASD	Preschool

Interview questions- Autism Research

- (1) Tell me how your child came to be diagnosed?
- (2) How long did it take for diagnosis from your first suspicions?
- (3) (a) When you became worried about your child's development who did you tell?
(b) What happened?
- (4) (a) When was the first time the term autism was mentioned?
(b) How did that make you feel?
Asd forum
- (5) (a) On the day of diagnosis, how do you feel about how you were told?
- (6) (a) How did the meeting end?
(b) How did you feel when you were leaving? (information & questions)
- (7) How do you feel now about how you got the diagnosis?
- (8) What suggestions would you make to improve the diagnostic service?
- (9) How satisfied are you with how the professionals came to the final diagnosis?

Are you; Very satisfied with the diagnostic service
Satisfied
Dissatisfied
Very Dissatisfied

INFORMATION LETTER TO DISCIPLINES

AUTISM RESEARCH PROJECT

SLT AUTISM RESEARCH GROUP

Phillippa Brooks

Amanda Byrne

Sinead Carthy

Breda Garvey-Cecchetti

Fionnuala Langford

Olive Laundon

Clare O Shaughnessy SLT Dept NUIG

Dear.....

The SLT Autism Research Group is planning a research project in association with the SLT Department in NUI Galway to begin in January 2007. It is part funded by an award from the Research Promotion Scheme of the National Disability Authority.

Our aim is to extend the research undertaken last year, which examined professionals' views of diagnostic practise of ASD in Co Mayo.

This project aims to explore Parents' perceptions and experiences of this service with a view to informing policies and procedures in this area. This is particularly relevant at this time as Community Services are moving towards a model of early intervention transdisciplinary team working for children with complex developmental needs.

Parents of children who have been diagnosed with ASD within the last two years will be invited to participate in this research.

There will be two aspects to the project. Clare O Shaughnessy, lecturer in the SLT Department, NUIG and a research assistant from NUIG will run Focus Groups. Themes emerging from the Focus groups will be followed up in individual interview sessions with a planned number of individual parents, conducted by Fionnuala Langford, Senior SLT.

The project is due to be completed by November 2007. A report will be submitted to the NDA and will also be disseminated locally.

If you would like any more information on this project, please do not hesitate to contact me, or any member of the SLT Autism Research Group.

Yours Sincerely

Fionnuala Langford
Senior SLT. Lead Researcher

