

**NORTHERN AREA HEALTH BOARD**

**Report No 51/2002**

**SERVICES FOR PERSONS**

**WITH AUTISM**

**December, 2002**

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# **REPORT ON SERVICES FOR PERSONS WITH AUTISM**

## **1. HISTORICAL DEVELOPMENT**

The assessment and diagnosis of children with autistic spectrum disorder was an integral component of the range of services provided by Children and Adolescent Psychiatrists and their multidisciplinary teams when the subspecialty of child and adolescent psychiatry was established. Likewise, support and development programmes for the children, their parents and siblings, were provided in and from the Child and Family Centres. As the child developed, he/she became integrated into developmental and educational programmes in special schools (primary education) for children and young people with autistic disorders, autistic disorders with mental handicap, organic disorders with associated severe behavioural disturbances and primary mental handicap with severe behavioural difficulties. These schools were funded by the Department of Education, whilst health and social support services were funded by the health service.

In the Eastern Region, educational and residential services were developed by the Mater Hospital (child and adolescent psychiatry), at St. Paul's Hospital, Beaumont, and by the Eastern Health Board at St. Loman's Hospital, Palmerstown. In the late 80s the residential unit at St. Loman's closed and community residential facilities were provided at James Connolly House, Blanchardstown; Dromheath Avenue, Mulhuddart, and Court Hall, Blanchardstown. This enabled the Board to develop specialist services for children with autistic disorders, as far as was practicable. A special school for children with autistic disorders was set up at James Connolly House, whilst residential and education facilities were set up for the children and young people with severe behavioural difficulties in Courthall.

The James Connolly House Special School and the Ballyowen Meadows Special School (Palmerstown) transferred to Beechpark, Stillorgan, in the mid-90s. This was a very significant milestone in the development of educational, and health and social support services for children with autistic disorders and their families in the Eastern Region. Since its inception, a clinical support team for both schools has been based at Beechpark. There are 47 children attending these schools at present; 6 from the Northern Area Health Board.

## 2. CURRENT SERVICE PROVISION - CHILDREN AND ADOLESCENTS

### 2.1 DIRECT SERVICE PROVISION

*Beechpark Services* endeavour to provide a comprehensive and co-ordinated clinical support service to children/adolescents on the autistic spectrum (those with a diagnosis of autistic disorder, asperger's disorder, and pervasive development disorder) up to the age of 18 years, their parents and siblings. Its catchment area spans the three area health boards - South Western, Northern and East Coast. The model of service delivery at Beechpark Services is multidisciplinary, i.e. Psychologist, Psychiatrist, Social Worker, Speech and Language Therapist, Nurse, Behaviour Specialist/Project Worker, Clinical Nutritionist.

The service works in partnership with the Department of Education and Science, parents/carers and all other relevant agencies, as necessary.

The service needs of children with autism are very complex and, in this regard, parents have had a major involvement in service planning over the years. Since 1998, in line with parental concerns and also following high profile court cases, the Department of Education and Science has developed a policy of integrating children with special needs (including children with autistic disorders) into mainstream education.

The Beechpark Services developed a community outreach response in the Eastern Region to support this policy. Three community multidisciplinary outreach teams were established - northside, westside, and southside. Arrangements were made with the management of primary schools, strategically based throughout the area, on the establishment of special classes (*Appendix I*).

The Beechpark regional services now provide for the needs of 361 children. Services include:

- outreach family support (e.g. early bird parent training, behaviour intervention);
- outreach clinical support to special classes - primary school;
- Beechpark campus (Ballyowen Meadows / Setanta Schools).

There are 125 children currently on the regional waiting list for services.

The number of children supported by the northside outreach team (Northern Area Health Board) is as follows:

Pre-school	19
Special Classes - Primary Schools	43
Waiting List	17
Mainstream Consults	20

Overview, including levels of learning disability - *Appendix II*.

## **2.2 VOLUNTARY SECTOR PROVISION**

*St. Paul's Hospital and Special School, Beaumont*, provides multi-disciplinary assessment, care and education for children and young people with autistic disorders, autistic disorders with intellectual disability, organic disorders with associated severe behavioural disturbances and primary intellectual disability with severe behavioural difficulties. In addition to residential care for 23 young people (18 on site in Beaumont and 5 in community house in Santry) and special education/day services for 46 young people (day and residential) the service provides respite care to other agencies for young people with severe and intractable behaviour problems. Of the 46 day/school attenders, approx. 65% are diagnosed with autistic disorder or diagnosed in the autistic spectrum (as the autistic spectrum is widening this figure is increasing) and 18 are in residential care.

Following the establishment of the Northern Area Health Board it was agreed to carry out a review of the St. Paul's Service, in collaboration with the management of the Mater Hospital. The outcome of the review and recommendations related therein were considered by our Board in early 2001. The recommendations dealt, in the main, with:

- the putting in place of appropriate governance arrangements;
- the strengthening of management;
- staff training and development;
- the formal involvement of parents in relation to service provision;
- the immediate improvement in the physical structures, furniture and décor of the centre.

## **2.3 ADULT SERVICE PROVISION**

The development and provision of services for adults in recent years reflects the involvement of the service in the Eastern Region with the parents and families of autistic children. Services for those aged 18 and over, which are provided on behalf of our Board by Gheel Autism Services and the Irish Society for Autism, are as follows:

*Gheel Autism Services* provide both day and residential care for adults with autism throughout the Eastern Region. Thirty-four adults are currently in receipt of life-long residential care in six community houses throughout the region. Five of these community houses are located in the Northern Area Health Board. A small number of clients are from outside the region.

Fairview	3 Houses (18 residents)
North Circular Road	2 Houses (11 Residents)
Sandyford	1 House with adjoining flat (9 residents)

There are seven respite places also available within these community houses.

Day services are provided in two centres – Fairview on the northside with 30 places and Milltown on the southside with 24 places.

Gheel Autism Services are also supporting a number of clients in employment on behalf of the three area boards.

Earlier in the year a review of Gheel Autism Services jointly commissioned by the Department of Health and Children and the ERHA was carried out. The recommendations contained in this report cover a range of service aspects including staffing levels, Board of Directors, management structure and systems, service model and standards, families/primary care givers and training and development.

The Department of Health and Children have allocated additional funding of €200,000 to Gheel Autism Services in 2003 to facilitate the implementation of the report.

*The Irish Society for Autism* provides residential services, on a national basis, at Dunfirth. At present, 20 of the 26 residential beds are occupied by persons from the Eastern Region. There are 3 clients from the Northern Area Health Board in Dunfirth at present.

### **3. SERVICE DEVELOPMENT FUNDING IN 2003**

€0.700M has been allocated to the region for the full year cost of service developments initiated in 2003 in respect of provision of health related support services for children with autism.

€0.500m for new service development funding has been allocated to the region in 2003 in respect of health related support services for children with autism.

Our Board is in continuous discussions with the Eastern Regional Health Authority (ERHA) in relation to securing the Northern Area Health Board's portion of the regional allocation.

In addition to the above, €0.200m has been allocated to the Authority in 2003 to increase the budget base for Gheel Autism Services.

#### 4. STAFF RECRUITMENT AND RETENTION

The Beechpark Services are experiencing difficulties in recruiting and retaining staff. The staff complement for the northside service is set out hereunder:

<i>Post</i>	<i>No. of Posts</i>	<i>Filled</i>	<i>Vacant</i>
Social Worker	1	1	-
Clinical Nurse Specialist	2	1	1
Behaviour Specialist	1	1	-
Occupational Therapist	2	-	2
Speech & Language Therapist	2	1 (On maternity leave - no locum)	1
Psychologist	1	-	1

The level of vacancies has a major impact on:

- the early home support programmes;
- wait list for services;
- capacity to provide support to children in the special classes (primary school).

The accelerated growth in service provision must also be taken into account in the context of staffing needs overall.

#### 5. FUTURE SERVICE PROVISION

##### 5.1 STRATEGIC DIRECTION

Senior managers from the ERHA and the three area health boards were involved in the development of a regional policy, which has since been adopted by the Authority in the report - *Review of Services for persons with Autistic Spectrum Disorder* (ERHA 2002). The main thrust of the recommendations in this report is to ensure that a comprehensive range of services is developed within each area board for persons with autistic spectrum disorder and that each board develop a management system for the delivery of autism services in its area. It is also recommended that Beechpark outreach services be reconfigured within the three area boards and the centralised regional referral system cease.

Since the development of the policy document, the funding for the Mater Child and Adolescent Service, including St. Paul's, has been transferred to our Board.

In keeping with the recommendations contained in the report, our Board has been involved in conjoint discussions with the South Western and East Coast Area Health Boards with a view to developing proposals for the future organisation and management of autism services within each area board.

It is important to acknowledge the major gains in service development and delivery that have been achieved in the collaborative and integrated approach involving the parents, health care and (education) teaching staff. In taking over the management and development of services, our Board is concerned that these gains are consolidated and strengthened to ensure ongoing development (in line with resource provision) and pursuit of quality in service delivery in the years ahead.

Discussions have taken place with the management of the Mater Hospital and the management of St. Paul's, Beaumont, with regard to the future direction of the St. Paul's service and also with regard to delivery of services focussed on the needs of clients within the range of autistic spectrum disorder. The management of St. Paul's were concerned that they would continue to deliver services within their existing parameters. However, in light of recent policy developments and with regard to the integration of autistic children into primary schools, and also the efficacy of the early bird support programmes, it is now opportune to review how best the St. Paul's Service can contribute to the overall needs of autistic children in the Board's area.

In developing future service provision, the following considerations will be taken into account by our Board: -

- There is now a greater awareness amongst parents and professional staff - health and education - of autistic disorder, the levels of need across the spectrum and the effectiveness of early diagnosis and focussed multi-disciplinary and educational programmes.
- In order to meet the life needs of each client, it is important that our Board's services in the future are informed by all relevant stakeholders - parents, maternity services, paediatric services, child & adolescent psychiatry, adult psychiatry, intellectual disability, educational, vocational/training.
- There is a lack of clarity at present in relation to assessment/diagnosis - protected sessions (Child Psychiatrist, Psychologist, Speech & Language Therapist, Occupational Therapist, Social Worker, Nurse) should be available to ensure timely and holistic assessment and the putting in place of care/educational pathways. Our Board considers that a Consultant Paediatrician should also have an important role in the multi-disciplinary team in the context of early diagnosis.

- In keeping with the person-centred requirements of the Health Strategy and the individual needs of each adult client, it is important that the commitment of stakeholders should be inclusive rather than exclusive in line with the requirements of individual care paths.
- Existing vacancies, as shown, in the northside outreach team is a matter of concern. Our Board's capacity to strengthen and further develop the team to meet current and growing service needs has to be seen in the context of recruitment (availability) across all key professions.
- There are now major pressures on the Beechpark Services for placements and community support services and the Service has found it necessary to review its admission criteria and prioritise intake to those most in need of a service.

*M. Windle*  
*Chief Executive*

*19<sup>th</sup> December, 2002.*