

CHAPTER 5

DIAGNOSTIC SERVICES AND EARLY INTERVENTION

This chapter focuses on the difficulties relating to the diagnosis of Autistic Spectrum Disorders and on educational intervention in early education for children prior to pre-school or nursery admission. Brief reference is also made to prompt post-diagnosis intervention for children who are older when they receive their diagnosis.

THE IMPORTANCE OF EARLY DIAGNOSIS AND EARLY INTERVENTION: INTRODUCTION

5.1 There is a consensus of opinion among professionals and researchers that early intervention, and therefore, early diagnosis, is essential to positive developmental and educational outcomes for the child with ASD. (Howlin and Rutter, 1987; Lovaas, 1987; Mesibov, 1997). The Task Group endorses the concept of early intervention as crucial to positive long-term prognosis, and consequently finds that diagnosis should secure prompt access to educational, health and social services. Diagnosis and intervention, in the view of the Task Group, should be formally linked to a given timescale, and parents should not have to wait, or to pay privately, for services to ensure their child's progress.

5.2 In their submissions to the Task Group, parents expressed concern at the "piecemeal provision" of diagnostic services across Northern Ireland, and the length of time taken to identify or to confirm diagnosis of autism: in particular, the parents of children with Asperger syndrome were angered at the endless visits made to a variety of professionals before a diagnosis was achieved for their child. The statementing process was criticised for the time lost from referral to the production of the statement. A central criticism was the lack of formal links between the ELBs and the various Health and Social Services Trusts.

5.3 The responses to the Task Group from the Health and Social Services Trusts provide a picture of variable services across Northern Ireland. The Trusts identified a number of shortcomings which include:

- ❖ a lack of resources, including designated ASD staff, to support families of children with ASD;
- ❖ ad hoc arrangements to deliver the family support;
- ❖ a lack of educational input on some diagnostic teams;
- ❖ an unwieldy system of referral;
- ❖ a lack of training of health staff, particularly Health Visitors;
- ❖ a lack of intervention services to refer children to after diagnosis;
- ❖ insufficient staffing, particularly clinical psychology and speech and language therapists;
- ❖ tentative links with the ELBs.

5.4 One submission to the Task Group from a Trust stated:

“Overall the provision for children with autism is dire - anything that has been developed, has been developed within resources and has put intolerable pressure on all professionals concerned.”

5.5 This statement highlights the current constraints under which some Trusts operate and it is significant, as another submission states, that services for children with autism are not identified in the Programme for Government and DHSSPS Priorities for Action for the coming year. The same submission adds:

“Unless next year’s priorities can be influenced (at Assembly Level) the likelihood of any service development for this group of children is negligible.”

5.6 On the positive side, a number of Trusts have established multi-disciplinary services for ASD, are beginning to make good progress in early identification of autism and are providing support to families and children in co-operation with the ELBs and voluntary agencies. One Health and Social Services Board, for example, has appointed an Early Intervention Therapist, and has begun to clarify the role of the health visitor to support services to the ASD population. Several multi-disciplinary teams currently operate to confirm diagnosis, though it is notable that the teams do not share a common or consistent approach to their work and variation in practices are common. In a number of Trusts, formal and informal links between the Health services and the educational psychology services or pre-school teacher/advisors for ASD, are helping to create more effective structures for providing services. Training of staff is under way in all Trust areas. The overall evidence is that there are serious limitations in relation to:

- ❖ the development of similar diagnostic and intervention services for all areas;
- ❖ the breadth and range of ASD training necessary to equip professionals adequately to cater for the needs of children with ASD;
- ❖ the need to identify a budget allocation to develop ASD services.

5.7 Howlin and Moore (1997) indicate the average age for diagnosis of autism as 5.5 years and 11.3 years for Asperger syndrome. In Northern Ireland the experience of many parents who responded to the Task Group indicated that parents often have to fight for the services and as a consequence feel that “they are a nuisance and can feel very isolated”. Parents report that they frequently find themselves in confrontation with professionals, particularly when seeking a statement of special educational needs which they regard as the only means of guaranteeing the support and resource their child needs. Professionals for their part are sometimes ill-trained to respond to the unique demands of identifying ASD and provision as a result is

limited and often variable. This situation is understandable given the extensive amount of research information emerging about autism.

5.8 It is evident from the literature that autism can manifest itself from before the age of 2 and can be identified from this stage by appropriately trained and experienced professionals. It is, however, important to take account of the fact that some children with ASD may not be identified early because of variability in the onset and severity of the condition. Internationally there is considerable consensus of opinion that the needs of children with ASD are very different and complex and therefore a full picture of these needs is best obtained by assessments which involve professionals from a variety of disciplines. In Northern Ireland, there is much evidence of closer liaison and collaboration among professionals and between agencies eg paediatricians, clinical psychologists and speech and language therapists and others within Health and Social Services Trusts, and between Health and Social Services Trust professionals and those from the Education and Library Boards, such as educational psychologists and specialist teachers/advisory officers. The terms multi-disciplinary and multi-agency are used below to describe these patterns of liaison and collaboration.

5.9 Evidence from parents and from the Trusts reveals that professionals use a range of diagnostic tools to assist their diagnosis of autism. Respondents to the Diagnostic Scoping Study commissioned by PAPA (Moore et al 1998 page 28) listed over 40 instruments in use in Northern Ireland. Many of these are tests of developmental level, cognitive skills and attainments (eg Griffiths Developmental Assessment, and tests from the Weschler range) which are not autism-specific instruments. Many are tests, checklists and diagnostic interview schedules which have been designed specifically with the assessment of ASD in mind (eg the Psycho-Educational Profile, the Childhood Autism Rating Scale, and the Parent Interview for Autism). More recently a number of professionals have undergone training on the use of the Diagnostic Interview for Social and Communication Disorders (DISCO).

RANGE OF PROVISION FOR DIAGNOSIS AND EARLY INTERVENTION WITHIN EACH EDUCATION AND LIBRARY BOARD

5.10 A brief description of diagnostic and early intervention services is outlined below and, while it is not intended to be a comprehensive evaluation of these services, the description helps to indicate the gaps in the current level of provision, and the improvements needed to establish an effective service to support children from the point of diagnosis until pre-school entry.

Belfast Education and Library Board (BELB)

5.11 Two multi-disciplinary and multi-agency clinics have been established recently in the Belfast area, one in the North and West Trust area and one in the South and East Trust area. At these clinics a range of professionals from Education and Health and Social Services collaborate to identify and assess the individual needs of children with ASD and to co-ordinate follow-up support from health, social services and education. The range of provision offered in the BELB area includes:

- ❖ The Keyhole Early Intervention Project, which is administered by Parents and Professionals and Autism (PAPA) and involves partnership with the South and East Trust.
- ❖ The Belfast Board's Pre-school Home Intervention Service, which was established in 1987, provides support to families of children with significant developmental delays. Educational psychologists make referrals to the service. The children are usually supported until they are old enough to attend mainstream or specialist nursery provision. In recent years an increasing proportion of these children have a diagnosis of ASD.
- ❖ The Oakwood Support Team was established in January 2001, and is located at Oakwood Special School. It presently consists of one full-time and one part-time ASD support teacher but a second full-time

teacher is being appointed. This service provides support to families of children with ASD, and will in due course take over support for children with ASD from the Pre-school Home Intervention Service. The service also provides support in nursery settings and in primary schools.

- ❖ In the Educational Psychology Service 2 psychologists, supervised by a senior educational psychologist, take a special interest in ASD and provide a lead in the dissemination of information and advice and participate in the multi-agency diagnostic and early intervention activities.

Despite recent developments, the Belfast Board's services are being outstripped by the increasing demands made on them, and they are not always able to provide the breadth and depth of input that may be requested by the parents or indicated by the individual needs of the child.

Western Education and Library Board (WELB)

5.12 In the Western Education and Library Board 2 educational psychologists take a leading role in responding to ASD and they liaise with health personnel to support diagnosis and assessment. Assessment information is collated and a clinic operates to confirm diagnosis. The clinic is inter-agency but not multi-disciplinary (ie the educational psychologists and a Community Medical Officer are involved but other professions are not). A major limitation of the current service is the geographical location of the clinic which serves children from the Foyle HSST area and is unable to address the needs of children from other parts of the board area. In the southern part of the board children may receive diagnoses from individual health service professionals.

5.13 Referrals from the clinic are made to the special education section of WELB which offers a pre-school support service for children with special educational needs including ASD. The pre-school service is co-ordinated by a senior peripatetic teacher. In addition, one teacher

from each of 5 special schools also contributes to the service. Every teacher has received basic training in ASD and possible intervention strategies. They set education targets based on detailed psychological reports and their own assessments. These targets are usually followed-up on a fortnightly basis. This service is available throughout the board area.

5.14 It is evident that diagnostic services are less available in some parts of the board's area and intervention provision may not be available for all children with ASD who need it. The survey of prevalence in Chapter 4 indicates that there may a significant number of children with ASD in the area who have not had a diagnosis.

North Eastern Education and Library Board (NEELB)

5.15 The Homefirst Health and Social Services Trust provides a multi-disciplinary diagnostic service but this Trust does not cover all of the NEELB area. This clinic is not a multi-agency clinic as there are no representatives from the Education and Library Board (ie the Educational Psychology Service is not directly involved in the clinic). There are plans, however, to establish in the near future 3 diagnostic teams which will involve collaboration among paediatricians, a clinical psychologist, a specialist speech and language therapist and educational psychologists. The teams will be based in the Newtownabbey/Carrickfergus area, the Antrim/Ballymena area and the Magherafelt/Cookstown area. The Trust plans to train health visitors in the use of ASD screening procedures for children at age 18 months and 30 months. Referral following diagnosis is made to the NEELB Educational Psychology Service which administers the pre-school service. The Causeway Health and Social Services Trust has identified the need for a diagnostic service for ASD. Resource limitations may determine that service developments may at first be inter-agency and not multi-disciplinary, ie similar to the model operating in Foyle HSST area.

5.16 The pre-school service is managed by a senior educational psychologist. It caters for children with special educational needs including ASD. Two full-time pre-school teachers are employed. The pre-school service also includes the home-school liaison teachers from

the 6 SLD special schools who carry out the pre-school work as part of their post. Children who have a diagnosis of ASD or are suspected of displaying some of the associated traits are often assigned to teachers from the special schools because of their knowledge and experience of ASD.

5.17 The survey of prevalence in Chapter 4 indicates that there may be a significant number of children with ASD in the NEELB area who have not had a diagnosis and may therefore not be receiving the pre-school intervention that they need.

South Eastern Education and Library Board

5.18 The Down Lisburn Trust operate weekly clinics in Ballynahinch and Lisburn and they report a 12 month waiting list. The clinics are multi-disciplinary but not multi-agency, ie clinical psychology, speech and language therapy and a senior clinical medical officer participate but there is no direct involvement by the education and library board. After diagnosis referrals are made to the educational psychology service.

5.19 Some of the SEELB area is covered by the South and East Trust, which also covers part of Belfast. The Educational Psychology Service has been participating in the development of the recently established multi-disciplinary, multi-agency ASD clinic in the South and East Trust. Provision in the SEELB area includes:

- ❖ The Keyhole Early Intervention Project accepts referrals from the Down Lisburn Trust clinic and the South and East Trust, but this project is now working to full capacity and cannot accept further referrals.
- ❖ The South Eastern Board's pre-school service comprises one senior peripatetic teacher and one other full-time teacher who has had training in ASD, but in addition the service is supported on a part-time basis by one teacher from each of 4 special schools. Home-based support is provided on a weekly or fortnightly basis according to need.

5.20 The rate of diagnosis in the Down Lisburn Trust area is the highest in Northern Ireland (see Chapter 4). The Trust has identified ongoing post-diagnosis support to families as an area of concern, noting that it is resourced to provide support where the child also has severe learning difficulties, but has more difficulty giving adequate support to more able children with ASD.

Southern Education and Library Board (SELB)

5.21 The Southern Health and Social Services Board and the Southern Education and Library Board are currently providing a Specialist Assessment Clinic in the Newry and Mourne Trust. This service caters for children up to 11 years old. In addition to this an Attention, Behaviour and Communication clinic is being piloted over a 2 year period and evaluated by the University of Ulster. It will provide a diagnostic and early intervention service on an area-wide basis for 14 children aged up to 3 years. Both clinics are multi-disciplinary and multi-agency. An Assistant Advisory Officer from SELB, who is a full-time ASD specialist with a teaching background, is a member of the clinical team with educational psychology joining with speech and language therapy, occupational therapy, community paediatrics and child and adolescent psychiatry to complete the mix of expertise.

5.22 The Health Board has employed an Early Intervention Officer to work specifically for the project. The main role of this officer is to gather information from parents with regard to the child and, in the case of the Specialist Assessment Clinic, carry out a follow-up visit, post-diagnosis. In the Attention, Behaviour and Communication clinic the Early Intervention Officer contributes to and implements the early intervention programme as recommended by the clinical team members, and gathers data as required for the independent evaluation process.

TRAINING IN DIAGNOSIS AND THE ASSESSMENT OF NEEDS

5.23 There is considerable variation across health and education board areas about the role of different professionals in the diagnosis of ASD, the terminology used to describe ASD, and in the criteria and diagnostic tools used. The professional who provides the diagnosis

may be a psychiatrist, a clinical psychologist, a paediatrician, or, very rarely, an educational psychologist. Increasingly the diagnosis is provided after consultations involving a range of professionals, including, for example, those mentioned above and on occasion, speech and language therapists, occupational therapists, social workers and teachers. Even where there has been multi-disciplinary consultation, the responsibility to diagnose may still lie with one professional, eg the paediatrician. The Task Group considers that diagnosis should be a multi-disciplinary multi-agency process, and that input from educational psychologists should be integral to the process in order to ensure appropriate assessment of special educational needs.

5.24 The main diagnostic tools in use include the DSM-IV criteria, which originate in the USA, and the ICD-10 criteria, which are commonly used in Europe, but individual practitioners are also influenced by their own preferences and a range of assessment tools are currently used. Many professionals, for example, use Gilberg's criteria to diagnose Asperger syndrome and often use a combination of assessment tools to confirm their findings. This variability in practice is accompanied by considerable professional and inter-professional debate. This debate is perhaps an inevitable, and healthy, characteristic of a field which is going through a period of rapid change and development. The rate of detection of ASD in Northern Ireland is rising rapidly, as it is in other countries. However, parents and teachers of children with suspected Autistic Spectrum Disorders will no doubt argue that the professionals involved should move as rapidly as possible towards agreed common diagnostic policies and practices. Movement towards this objective will be influenced by opportunities for co-ordinated multi-disciplinary training. The Task Group regards common diagnostic training as a significant step towards a multi-disciplinary model of identification and intervention of ASD.

5.25 The number of local professionals trained in the diagnosis of ASD was boosted in 1997 and 1998, when PAPA and the Northern Ireland Child Health Group arranged for courses to be provided in Northern Ireland by the National Autistic Society. Twenty-four people from a range of professions attended these courses and many of these went on to develop and/or participate in

diagnostic services. A number of this group have recently had further training on the DISCO diagnostic procedure. Only 2 of the participants in these courses were Educational Psychologists. Many more Educational Psychologists have attended courses on methods of assessing and meeting the needs of children with ASD. The initial training course for Educational Psychologists at Queen's University includes a unit on the assessment of the special educational needs of children with ASD.

5.26 PAPA continues presently to facilitate training in diagnosis to local practitioners. Not all training, however, is centrally co-ordinated, and individual professionals frequently seek out and attend courses which they consider appropriate to their needs. There is little centralised strategic planning in relation to training in the statutory sector.

5.27 More recent forms of assessment include the Checklist for Autism in Toddlers (CHAT) to screen young children from the age of 18 months. Health Visitors in the NEELB area are to be trained in the use of the CHAT in the near future.

5.28 The Southampton Assessment Service (Moore, V. et al, 1998) has been commended to the Task Group as a service which incorporates many good practices. In the Southampton model, following collation of information, parents have a multi-disciplinary assessment and feedback on their child in one day, and access to a member of the local autistic society who provides them with further information about their services including the involvement of an outreach worker from the charity to support the family. In addition, the inclusion of an ASD experienced teacher in the multi-disciplinary assessment team allows for further classroom-based assessment, which enables a more informed assessment of the type of intervention programme required, matched to the child's ASD needs and incorporating an age-appropriate curriculum. The strength of this model lies in the opportunity provided for immediate comparison of perspectives among a number of different observers including the parents. This facilitates speed, thoroughness and accuracy of diagnosis. The service, however, is an assessment service and as such it is restricted in the extent to which it can implement

recommendations related to likely educational needs and strategies for behaviour management (Moore V. et al, page 126). The Task Group notes that diagnostic services in Northern Ireland already recognise that it is essential to follow-up diagnosis with immediate arrangements for high quality multi-disciplinary, multi-agency support for the child and the family.

SUBMISSIONS FROM TRUSTS, EDUCATION AND LIBRARY BOARDS AND OTHERS

5.29 Submissions to the Task Group from a number of Trusts and the ELBs indicate that professionals are aware of the gaps in the provision for ASD, and several Trusts and ELBs are currently reviewing their provision. The Task Group identifies the following areas which should be addressed by the Department of Education and the Department of Health, Social Services and Public Safety, if services are to meet, more effectively, the needs of the ASD population at an early age:

- ❖ the need for greater collaboration across Trusts and ELBs to develop equity of provision and to establish clear referral pathways and time scales for response to referrals;
- ❖ the need to increase the number of more dedicated multi-disciplinary, multi-agency ASD clinics to provide localised services;
- ❖ the need to clarify the various roles of diagnosis and assessment team members within each Trust/ELB area;
- ❖ the need to develop high quality ASD early intervention services from the point of diagnosis until the child enters pre-school or mainstream education;
- ❖ the need to develop further diagnostic and follow-up services for older children and young adults who may have missed out on the opportunity for diagnostic assessment because of the relative absence of such services until recent years;

- ❖ the need for training for all staff involved in working with children and young people with ASD;
- ❖ the need to identify funding and the deployment of resources specifically for ASD services (in the way, for example, that this is already done for children with Severe Learning Difficulties).

5.30 In their submission to the Task Group, PEAT suggest that early diagnosis should involve:

- ❖ assessment within 4 weeks of referral;
- ❖ home-based assessment by a multi-disciplinary team;
- ❖ referral to a gastroenterologist;
- ❖ the nomination of a social worker to co-ordinate family support;
- ❖ the need for counselling support at the point of diagnosis.

5.31 Strain (2000) highlights the difficulties of early assessment for children under 2 years who may also have severe developmental delays. Assessment may not indicate many strengths, and this may make it difficult to be certain about whether there are specific deficits in social and communicative functioning and play.

5.32 The Task Group endorses the stages of early recognition and diagnosis of autism as proposed by the National Early Childhood Technical Assistance System (NECTAS) working group (Shaw, Oser and Berman 2000, quoted in P Strain's submission paper to the North-South special education representatives in November 2000) and recommend the following stages of ASD recognition:

- ❖ public and professional awareness of autism and the importance of its early diagnosis;

- ❖ early home-based screening for ASD using the CHAT or appropriate tool, by an ASD-trained professional, most likely the Health Visitor;
- ❖ comprehensive diagnostic assessment by professionals, trained and experienced in ASD, to include observation of the child and the identification of methods of intervention matched to the needs of the child and the family.

5.33 Expertise in the assessment and diagnosis of ASD has developed recently and dramatically in Northern Ireland. General awareness of ASD has resulted in identification of children and adults with ASD at various stages of their educational, training and employment careers. The prevalence data provided in Chapter 4 indicate strongly that there may be many older individuals with ASD who do not have a diagnosis. Referral pathways for older children and young people are unclear, undefined and unprepared. Information and support is difficult to access as a result.

5.34 The Task Group endorses the emphasis on securing assessment and diagnosis of ASD as early as possible, but it also points to the need to address the needs of older pupils who have not had access to diagnostic services while they were young.

CHAPTER 5

**DIAGNOSTIC SERVICES AND
EARLY INTERVENTION****RECOMMENDATIONS****Recommendation 5(i)**

The Task Group recommends that the Departments of Education, Health, Social Services and Public Safety and Employment and Learning should establish an inter-departmental working party that includes representatives from all sectors of education, health and social services and the voluntary sector, to develop multi-disciplinary agreement and protocols on good practice in assessment, diagnosis and early/prompt intervention services for children and young people suspected of having an ASD.

Recommendation 5(ii)

The Task Group recommends the further development of diagnostic services so that they are characterised by the following features:

- ❖ early home-based screening by an ASD-trained professional such as a health visitor;
- ❖ clear referral pathways and prompt responses to referral;
- ❖ multi-agency and multi-disciplinary diagnosis and assessment of health, therapy, dietary, and special educational needs;
- ❖ involvement of parents in the diagnostic and assessment process;

- ❖ consistency across the boards in the range of professionals involved in diagnosis and assessment, in the specialist training to which they have been exposed and in diagnostic practice and procedures;
- ❖ prompt arrangements for co-ordinated multi-disciplinary, multi-agency support to the child and the family, based on needs identified during the diagnosis and assessment process.

Recommendation 5(iii)

The Task Group endorses the involvement of the following early intervention services after ASD diagnosis:

- ❖ the nomination of an ASD support worker as an advocate for each child and family;
- ❖ family support including training, counselling, home-based programmes and parental support groups;
- ❖ occupational therapy, physiotherapy and speech and language therapy and other support as appropriate from professionals allied to medicine;
- ❖ clinical and educational psychology services;
- ❖ social services, including respite;
- ❖ support with transport to and from early intervention services when necessary.

Recommendation 5(iv)

The Task Group recommends that DE should ensure that each ELB identifies an ASD Action Plan to address the needs of children with autism from the point of diagnosis. The Action Plan should include:

- ❖ a specific budget to develop provision for children with ASD;

- ❖ a strategic programme of intervention for children with ASD, including home- and centre-based provision;
- ❖ an early intervention programme tailored to the individual needs of the child and the family, as indicated by a comprehensive ASD multi-agency, multi-disciplinary assessment;
- ❖ an ASD support service to provide training, individual educational provision and support;
- ❖ an ASD Planning Team within each ELB to review the action plan and work in collaboration with the Trusts to ensure the delivery of a child and family support programme.

