DEPARTMENT OF EDUCATION
An Roinn Oideachais
Männystrie o Lear

INVESTOR IN PEOPLE

THE EDUCATION OF CHILDREN AND YOUNG PEOPLE
WITH AUTISTIC SPECTRUM DISORDERS

Report of the
Task Group on Autism

MINISTERIAL FOREWORD

As Minister for Education, one of my key priorities is special education. I believe strongly that all children should have the opportunity to achieve to their full potential, and that how we provide for the needs of those children who need extra help is a measure against which our education system should be judged. Within special education, I am continually impressed and heartened by the wealth of dedication, love, imagination and skill which teachers bring, day and daily, to their work with children, both in special schools and units and in mainstream classes. I believe that this expertise needs to be shared more widely within education; but also there is much more which needs to be done.

Research shows that autism and dyslexia are under-reported and under-developed aspects of special needs. These are issues which are of concern throughout Ireland. When the North-South Ministerial Council was established, special education was an immediate priority for both our Education Departments, and we decided that autism and dyslexia should be the areas for first attention. At the same time, parallel Task Groups were established in these areas here and in the South, and we were careful to ensure that membership of both groups overlapped so that experience and information could be shared to the benefit of all.

The North's Task Group on Autism was led by Mr Martin Clarke, Principal Educational Psychologist of the Belfast Education and Library Board, and he and his colleagues on the Group have produced a major and very comprehensive Report. I am particularly grateful to him personally, as well as to his colleagues, for giving so generously of their time and expertise. I would also like to acknowledge the valuable contributions of all those who offered their insights and expertise to the Group in its work; and also to express my thanks to the Belfast Education and Library Board for allowing Mr Clarke the time and administrative support to lead the Group and compile this Report.

It presents very real challenges for all of us in education, particularly in relation to under-diagnosis, and under-provision in the early years. It also highlights a number of areas where we need to take action, in terms of training for classroom teachers in recognising where a child has, or may have, a difficulty on the autistic spectrum; in understanding what this may mean in terms of how the child will behave, interact and learn; in putting in place measures to address the child's needs; in working with parents to ensure a consistent approach between school and home - and, most importantly, to ensure that the obstacles to learning presented by the autism are minimised. These challenges are life-long: for Further and Higher Education, for employers and for society, because autism is not a condition which disappears with maturity.

I very much hope that this Report will serve to inform our thinking, and to act as a catalyst to help us all in the education system reassess and improve what we do. I commend it to you and look forward to your response.

Martin Mc Guinness

MARTIN McGUINNESS MP MLA
Minister for Education

April 2002

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ACKNOWLEDGEMENTS

The Task Group would like to acknowledge the work of

Caroline Campbell, Senior Clerical Officer, BELB, who provided administrative support to the Task Group

and

Maria McAleese who was responsible for the survey of prevalence of ASD within the NEELB during her time there as an Educational Psychologist in Training.

December 2001

EXECUTIVE SUMMARY

The Task Group on Autism was established in November 2000 to make recommendations on educational provision for children and young people with autism. The Task Group recognises that children, young people and adults with autism require services from many different professions and agencies. Some of the recommendations, therefore, will not only be of relevance to the Department of Education, (DE), but also to the Department of Health, Social Services and Public Safety, (DHSSPS) and the Department for Employment and Learning (DEL).

Methods of Information Gathering and Task Group Structure

The Task Group members are educational practitioners with an interest and expertise in autism and included representatives of voluntary organisations. Among the participants were 2 Inspectors, one from the Education and Training Inspectorate (which serves 3 Departments) in Northern Ireland and one from the Department of Education and Science in the Republic of Ireland. The Inspectors were able to facilitate liaison between the Task Group on Autism in Northern Ireland and the Task Force on Autism in the Republic of Ireland.

The Group, through its members, consulted widely with a variety of professionals in Education and Library Boards and Health and Social Services Trusts and Boards and with parents and voluntary organisations across Northern Ireland. Consultation was achieved through interest group meetings, individual submissions, responses to surveys, and written and verbal requests for information. The Task Group also reviewed a wide range of literature on autism and invited experts on autism to address the Group. A full List of Consultees, Glossary and References can be found in the Appendices.

Terms of Reference

The Department of Education proposed the following terms of reference to the Task Group:

- to advise the Department of Education on the range of provision for children with autism across the Education and Library Boards;
- to identify training needs, training opportunities and indicators of good practice for teachers and, as appropriate, parents;
- to recommend a model of provision to promote consistency of approach to identification and service delivery across all boards;
- to produce a report to the Department on the above and, concurrently;
- to inform and learn from ongoing work on autism provision on a North-South basis; and
- to contribute as appropriate to the compilation of reports to Ministers of the North-South Ministerial Council. (Since the education sector of the North-South Ministerial Council did not meet again during the life of the Task Group, this element of the terms of reference was not brought into effect.)

Overview of the Task Group's Findings and Recommendations

The Task Group has found that within the last few years educational, health and social services provision for children and young people with Autistic Spectrum Disorders (ASD) has entered a period of rapid improvement in many areas of Northern Ireland. However, parents, voluntary bodies and statutory bodies alike recognise that there is still much progress to be made before it will be possible to say that all children and young people with ASD are being identified and that their needs are being fully met. There is, in particular, a demand for more prompt access to diagnostic services at an early age and that these services should be followed immediately by effective home- and school-based intervention. There is also considerable concern about provision for children with ASD and challenging behaviour. The report highlights the fact that there is an "autistic spectrum wave" rising through the school system, and that as it progresses there will be a large increase in the numbers of pupils, students and trainees with a diagnosis of ASD and a large increase in demand for appropriate services and educational provision.

The Task Group stresses the need for significant improvements in 3 main areas:

- access to multi-agency, multi-disciplinary diagnostic and assessment services;
- training for parents of, and people who work with, children and young people with ASD;
- school-based and home-based educational and therapeutic provision.

The Task Group findings indicate that children and young people with ASD, and their families, need support from people employed by a variety of statutory and voluntary organisations. The strategies for catering for the needs of individuals with ASD are primarily educational in nature. As a result, it will be necessary for the Department of Education to take the lead in establishing an inter-departmental group (see recommendation 5(i)) which should develop a strategic plan to be carried forward by the Education and Library Boards, Health and Social Services Boards and Trusts, Further and Higher Education Colleges and the Training and Employment Agency, in partnership with voluntary bodies. Each Education and Library Board should develop an ASD action plan (see recommendation 5(iv)), which is underpinned by adequate resources.

The Task Group (see recommendations 3(i) to 11(x)) makes many specific recommendations with respect to the types of services and educational provision which should be developed in order to support children and young people with ASD and their families. The Group finds preference for no single approach to meeting the needs of children and young people with ASD. The Group recommends that the development of provision should be underpinned by 7 basic principles which focus on diagnosis and assessment, on individual programme planning, delivery and evaluation, on training, and on respect for the needs and rights of the child and the family (see recommendation 3(iii)).

The Group regards education as the most effective means of addressing the needs of individuals with ASD, and contends that educational provision based on these 7 basic principles will command the respect of professionals and parents alike, and will promote the maximum development of the individual with ASD.

Summary of Recommendations

Chapter 1: Introduction to the Report of the Task Group on Autism

This chapter contains a brief account of the background and context of the report, both educational and legal. The chapter describes the research methodology and the membership of the group. It sets out the terms of reference for the Task Group.

Chapter 2: Overview of Autistic Spectrum Disorders: Implications for Educational Provision

In this chapter the essential features of Autistic Spectrum Disorders (ASD) are described in terms of a 'triad of impairments', ie the individual with ASD will experience impairments of social relationships, communication and imagination. The severity of these impairments can vary greatly thus giving rise to a spectrum of disorders.

The Task Group notes many implications of ASD for educational provision. The Group makes the following broad recommendations about how these implications should be taken into account by those who are engaged in planning and developing provision, in providing training for staff, and in teaching pupils and young people with ASD. Some of these recommendations are expressed in greater detail in later chapters.

Recommendation 2(i)

Educationalists should recognise that education has a central role in ‘remediating’ the effects of ASD and improving the quality of life for individuals throughout their lifespan.

Recommendation 2(ii)

The central factor in educating an individual with ASD is to understand the nature of the disorder in order to facilitate learning and social inclusion: teachers, parents and others planning educational programmes for individuals with ASD should have an understanding of ASD.

Recommendation 2(iii)

Early diagnosis should be available and should include an accurate and comprehensive assessment from which appropriate educational and health interventions are developed, and should also include identification of co-mordant conditions.

Recommendation 2(iv)

Teachers and others contributing to programmes should be provided with relevant information arising from the diagnostic assessment process.

Recommendation 2(v)

Comprehensive speech and language assessment and input to the programme is essential: the deployment and training of speech and language therapists should reflect this.

Recommendation 2(vi)

Social skills training should be provided as an essential element of intervention programmes for children and young people with ASD.

Recommendation 2(vii)

The learning strengths and weaknesses of children and young people should be identified to ensure effective differentiation of provision: an emphasis on visual communication, simple and clear use of language and constant routine are of particular value when teaching children with ASD.

Recommendation 2(viii)

Interventions should focus on the development of strategies which structure the environment to provide the child with a sense of security conducive to learning appropriate behaviours in a range of settings.

Recommendation 2(ix)

Teachers and others should understand the sensory difficulties which children may experience as a consequence of ASD and set appropriate targets to address each child's sensory needs.

Recommendation 2(x)

Intervention programmes should address the issue of anxiety and stress as a normal consequence of ASD.

Chapter 3: Approaches, Perspectives and Debates: Implications for Educational Provision

This chapter describes the most common approaches currently being used in Northern Ireland for meeting the needs of children and young people with ASD. The chapter also includes discussion of some of the associated debates and controversies; the issues in relation to intensity of provision and inclusion are also discussed. Implications are drawn.

The recommendations are as follows:

Recommendation 3(i)

The Task Group finds preference for no single approach but concludes that single methods by themselves may not address effectively the triad of impairments associated with ASD. The Group concludes that intervention programmes should be child-centred rather than method-centred, and should address the observed and unique needs of the child and any variation in these which occurs over time and across settings and situations.

Recommendation 3(ii)

The Task Group recommends that provision should include strategies and approaches matched to the needs of individual children and delivered in home-based and centre-based settings, as indicated by multi-disciplinary and multi-agency assessments in which parents are fully involved.

Recommendation 3(iii)

The Task Group recommends 7 principles to underpin planning of provision by the Education and Library Boards.

Provision should be:

- based on current research indicating best practice in respect of achieving meaningful outcomes, providing value for input of time and resources, and promoting independence and inclusion;
- inclusive of a range of methods and approaches which have been shown to be effective or which are judged by those who work with children with ASD to be worthy of evaluation;
- determined by, and regularly reviewed by, multi-disciplinary, multi-agency teams which include parents as well as appropriately trained professionals from the ELBs and HSSBs, and which respond promptly to requests for assessment and intervention;
- reflective of the individual's needs profile, and any changes in these needs over time and across different contexts and reflective of the needs of the family;

- compatible with the Department of Education's guidelines on pastoral care, including child protection (Circular 1999/10) and the United Nations Convention on Human Rights (Article 4);
- provided by appropriately trained professionals, and by parents who have also had appropriate training;
- subject to review, evaluation and inspection by the Education and Training Inspectorate.

Chapter 4: Prevalence and Incidence: International; Northern Ireland

This chapter is a review of international research on prevalence of ASD which is presented in conjunction with the results of a survey of prevalence rates in Northern Ireland. The data were gathered during the academic year 2000-2001. The Task Group conducted the survey to establish more clearly the prevalence rate in Northern Ireland, which was at that point in time unknown, yet it was felt that the rate was rising rapidly, and significant variations in prevalence existed between boards and across age groups. The recommendations are as follows:

Recommendation 4(i)

The maintenance by each ELB, HSST and HSSB and relevant Departments of compatible databases that can provide information necessary for planning - the Task Group recommends that the term Autistic Spectrum Disorders (ASD) be used to cover the whole range of difficulty, within which 2 subgroups - Autism and Asperger syndrome, and no other terms - should be used.

Recommendation 4(ii)

ELBs and Trusts should collaborate to consider the variation in prevalence of ASD from area to area, and to develop diagnostic services which ensure equality of access regardless of home address.

Recommendation 4(iii)

ELBs and Trusts should collaborate to consider the low detection rates for very young children and for older children, and to develop diagnostic services which ensure equality of access regardless of age.

Recommendation 4(iv)

ELBs and Trusts and providers of Further and Higher Education, training and employment should plan for significant increases in the demand for provision for individuals with ASD.

Chapter 5: Diagnostic Services and Early Intervention

The consensus among experts on ASD is that early diagnosis and support is of great importance if the best outcome is to be achieved. This chapter seeks to identify the extent to which existing provision and services achieve this. The survey of provision of diagnostic services across the 5 ELB areas along with a survey of the post-diagnosis follow-up arrangements for children and their families indicates significant variability from area to area. The chapter focuses primarily on family-based support for young children before they begin to attend pre-school or nursery provision. The recommendations are as follows:

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 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.

Chapter 6: Nursery and Pre-School Provision

This chapter investigates the availability and effectiveness of the developing support services for children with ASD in nursery and pre-school provision. A survey of these support services is presented. The recommendations are as follows:

Recommendation 6(i)

The Task Group recommends that the Department of Education should ensure that ELBs, Trusts and voluntary organisations significantly develop services for pupils of nursery school age so that they include the following features:

- early assessment and regular review by multi-agency, multi-disciplinary teams involving parents;
- access to suitable mainstream nursery/pre-school placement;
- access to specialist nursery/pre-school placement if required;
- provision of a comprehensive and adequately resourced programme by trained staff, implementing an individual education plan which addresses the child’s needs and maximises educational and social inclusion;
- access to appropriate levels of training for all staff - the training needs of staff will vary according to circumstances - the training available should match their identified needs;
- provision of educational advice, training and support from an adequately resourced ASD specialist service, to include help as required from appropriately trained and supervised classroom assistants;

- access to therapy and advice from professionals allied to medicine, to include support with the development of the child's individual education plan;
- carefully structured and adequately resourced programmes to ensure smooth transitions into the nursery or playgroup and on into primary education;
- home-school programmes which encourage the full involvement of parents.

Recommendation 6(ii)

The Task Group recommends the revision of current admissions criteria for nursery schools to ensure that children with special educational needs, such as ASD, are given priority.

Chapter 7: Primary Provision

In this chapter it is recognised that most children known to have ASD are currently being educated in primary schools including special units and in schools for children with moderate learning difficulties (MLD) and other difficulties. A survey of the support provided is presented. The recommendations are as follows:

Recommendation 7(i)

The Task Group recommends that the Department of Education should ensure that ELBs, Trusts and voluntary organisations significantly develop services for pupils of primary school age so that they include the following:

- early assessment and regular review by a multi-agency, multi-disciplinary team involving parents;
- access to suitable mainstream placement;
- access to special unit placement when required, and for as long as required, subject to regular review - the needs of some pupils with ASD may be met in MLD units or Speech and Language Units but some pupils

may require placement in a unit specially designed to meet the needs of pupils with ASD;

- access to special school when required, and for as long as required, subject to regular review - the needs of some ASD pupils may, for example, be met in MLD schools or in schools which cater for children with communication difficulties or medical difficulties;

- provision of a comprehensive and adequately resourced programme by trained staff, implementing an individual education plan which addresses the child's needs and maximises educational and social inclusion;

- access to appropriate levels of training for all staff - the training needs of staff will vary according to circumstances, and the training available should match their identified needs - staff in special schools and units for children with MLD, speech and language problems and health problems will have particular need of training since they work frequently with pupils with ASD;

- provision of educational advice, training and support from an adequately resourced ASD support service, to include help as required from appropriately trained and supervised classroom assistants;

- access to therapy and advice from professionals allied to medicine, to include support with the development of the child's individual education plan;

- carefully structured and adequately resourced programmes to ensure smooth transition into year 1 and on to post-primary education;

- home-school programmes which encourage the full involvement of parents;

- summer schemes appropriate to the needs of ASD children.

Chapter 8: Post-Primary Provision

This chapter surveys the types of difficulties experienced by pupils with ASD in the post-primary sector attending schools other than SLD schools, and surveys the provision made for them. The Task Group notes that there will be a significant increase in the number of such pupils in the near future and, therefore, a significant increase in demand for appropriate support and provision.

Recommendation 8(i)

The Task Group recommends that the Department of Education should ensure that ELBs, Trusts and voluntary organisations significantly develop services for pupils of post-primary school age so that they include the following:

- continuing assessment and regular review by multi-agency, multi-disciplinary teams involving parents;
- access to suitable mainstream placement;
- access to special unit or placement when required, and for as long as required, subject to regular review - the needs of some pupils with ASD may be met in MLD units or Speech and Language Units but some pupils may require placement in a unit specially designed to meet the needs of pupils with ASD. These units may be attached to designated secondary schools;
- access to special school when required, and for as long as required, subject to regular review - the needs of some ASD pupils may, for example, be met in MLD schools or in schools which cater for children with communication difficulties or medical needs;
- ASD resource bases in schools to support pupils unable to integrate fully into mainstream classes and to provide additional advisory and practical help to all members of staff - such bases should in turn be supported by the ASD support service;

- residential provision for some pupils, which maintains high levels of involvement of parents and staff from the mainstream school and works towards reintegration;
- provision of a comprehensive and adequately resourced programme by trained staff, implementing an individual education plan which addresses the child's needs and maximises educational and social inclusion;
- access to appropriate levels of training for all staff - the training needs of staff will vary according to circumstances, and the training available should match their identified needs - staff in special schools and units for children with MLD, speech and language problems and health problems will have particular need of training since they work frequently with pupils with ASD;
- provision of educational advice, training and support from an adequately resourced ASD support service, to assist post-primary pupils to integrate and benefit from mainstream placement;
- access to therapy and advice from professionals allied to medicine, to include support with the development of the child's individual education plan;
- close co-operation between education and health professionals to ensure that the social and emotional needs of pupils with ASD are jointly planned for within a personal social education programme including individual counselling when necessary;
- carefully structured and adequately resourced programmes to ensure smooth transition into Further and Higher Education, training and work placements;
- home-school programmes which encourage the full involvement of parents.

Chapter 9: Provision for Children with ASD and Severe Learning Difficulties

This chapter considers the needs of children with ASD in combination with Severe Learning Difficulties (SLD), children whose needs are likely to be different from those of children with ASD alone. A survey of support for children attending SLD schools is presented, and good practice noted. The recommendations are as follows:

Recommendation 9(i)

The Task Group recommends that staff in SLD schools should have access to a range of training provision to meet their various needs and provided by the ELBs in co-operation with voluntary associations, ASD support services and other training providers, for example, universities. This provision should include:

- whole-school training in ASD;
- training in a variety of teaching methods and approaches;
- training in behavioural techniques;
- access to conferences and workshops for ASD provided by agencies.

Recommendation 9(ii)

The Task Group recommends that SLD schools should have:

- a staffing ratio of one teacher and 2 classroom assistants to 6 pupils identified with an ASD; and additional staff to meet the needs of pupils experiencing severe challenging behaviour as indicated by multi-disciplinary assessment;
- appropriate accommodation to meet pupils' needs;
- sufficient additional equipment to meet the needs of pupils with ASD;

- speech and language therapists appointed to their staff;
- access to occupational therapy with ASD specialist knowledge;
- access to music therapy;
- adequate funding to run ASD-specific summer schemes.

Recommendation 9(iii)

The Task Group recommends that SLD schools should maintain:

> Home-school ASD programmes which encourage the full involvement of parents.
>
> Partnership links with voluntary associations in order to avail of their services and support.

Chapter 10: Provision for Children with ASD and Challenging Behaviour

This chapter considers the challenge presented to those who have to meet the needs of children and young people whose aggressive or withdrawn behaviour may prevent learning. Children with ASD can behave in ways which are sometimes difficult to understand and in extreme cases can be dangerous or disruptive to others in school and at home. The recommendations are as follows:

Recommendation 10(i)

The Task Group recommends that a range of differentiated provision, including resources, should be made available to meet the needs of children with ASD and challenging behaviours, and should be sufficiently flexible to allow the child to avail, where recommended, of different placements, including specialist and residential provision. The range of provision should include:

- an ASD/challenging behaviour referral unit for pupils unable to integrate fully into their school and situated to serve the needs of a geographical sector of schools;
- residential provision, short- and long-term, with an emphasis on reintegration.

Recommendation 10(ii)

Training in identifying and managing children with ASD and challenging behaviours should be provided for parents, teachers and classroom assistants.

Recommendation 10(iii)

Multi-agency and multi-disciplinary support and comprehensive assessment of the child and of the ecology of the classroom should be available to all schools experiencing challenging behaviours to assist staff in the creation of a positive environment and the implementation of effective programmes.

Recommendation 10(iv)

Research should be funded to clarify the complex needs of this population, and identify the types of resources and approaches which are most effective.

Recommendation 10(v)

The Departments of Education and Health, Social Services and Public Safety should seek to establish protocols and guidance on collaborative working at ELB and Trust level.

Chapter 11: Further and Higher Education, Training and Employment

This chapter considers the current and future requirements of young people with ASD in relation to training and employment needs. The providers of Further and Higher Education and of training and employment are aware of only a small number of young people with a Diagnosis of ASD; the survey of prevalence (Chapter 4) indicates that this number will increase over the next few years. A survey of the services currently available for young people with special needs is presented and good practice is noted. The recommendations are as follows:

Recommendation 11(i)

Training

All staff working with people with ASD should be well trained within a co-ordinated training framework which makes use of the expertise in the education sector and includes the key agencies and the voluntary sector.

Recommendation 11(ii)

Expert Group

A Reference Group of Professionals should be established, representing the various agencies and the voluntary sector, who would advise and support on ASD issues.

Recommendation 11(iii)

Multi-Disciplinary Approach

People with ASD should have access to a multi-disciplinary service to assist their post-school placement. This may include psychiatrists, social workers, speech therapists, occupational therapists and psychologists.

Recommendation 11(iv)

Late Diagnosis

Diagnostic services for young people and adults should be improved in order to reduce the number of young people and adults with ASD who do not have a diagnosis.

Recommendation 11(v)

Support Service

A support service, to include access to a residential facility where necessary, should be established, for individuals with higher functioning autism or Asperger syndrome to ensure their successful completion of Further and Higher Education.

Recommendation 11(vi)

Funding for Further Education

Individual funding packages should be provided for students with ASD to ensure that colleges can effectively provide for their education.

Recommendation 11(vii)

Statistical Information

DEL should develop a database to identify numbers in Further and Higher Education, training and employment. This information should inform the future planning of services.

Recommendation 11(viii)

Training/Employment Support

In order to build up experience and expertise in supporting people in employment, a specialist approach needs to be adopted. A number of support workers should specialize in order to build up expertise in working with people with ASD, a number sufficient to ensure that all people with ASD can have access to an appropriate level of support.

Recommendation 11(ix)

North-South Opportunities

Exchange visits, seminars and conferences should be set up to bring people together, establish networks and generally give more support to people working in this area.

Recommendation 11(x)

Transition Planning

The Transition Planning process should be improved in order to ensure the effective involvement of all relevant professionals and parents. Apart from educational provision it should address the areas of social and life skills, behaviour, environmental needs, risk assessment and support needs. A profile of information gathered throughout their school life should follow the pupil to any new provision.

CHAPTER 1

INTRODUCTION TO THE REPORT OF THE TASK GROUP ON AUTISM

This chapter describes the origins of the Task Group, its membership, terms of reference, and methods of information gathering and considers some relevant educational and legal factors. The structure of the report is outlined.

BACKGROUND AND CONTEXT

1.1 In recent years, parents and educationalists throughout the island of Ireland have become increasingly concerned about the adequacy of services for children with autistic spectrum disorders. In recognition of this concern, in November 2000, the Department of Education established the Task Group on Autism. Separately from the work of this group, in the Republic of Ireland, a Ministerial Task Force on Autism was established. The Task Group on Autism was initially asked to report to the Department by the end of March 2001, but due to the magnitude and complexity of the task the Group were unable to complete their report until December. The South’s Task Force on Autism, faced with similar problems, were unable to complete their report until November 2001.

Educational and Legal Context

1.2 Education and Library Boards (ELBs) and schools and others exercising relevant statutory functions have a statutory duty under Article 4(2) of the Education (NI) Order 1996 to have regard to the Code of Practice on the Identification and Assessment of Special Educational Needs. The Code of Practice has been operative since September 1998.

1.3 The Code of Practice indicates that a staged approach should be taken to the assessment of special educational needs and to arranging appropriate educational provision for children of compulsory school age. At stages 1 and 2 the class teacher and the Special Educational Needs Co-ordinator should consider the pupil's special needs and arrange provision. At stage 3 the school may seek external support from specialists such as educational psychologists and peripatetic teachers. Where these measures do not result in adequate progress the ELB may, at stage 4, make a statutory, multi-disciplinary assessment. At stage 5 the ELB may make a statement of special educational needs and arrange, monitor and review special educational provision. Throughout the Code, emphasis is given to the importance of parental involvement in the processes of assessment and the implementation and regular review of an educational plan for the child.

1.4 For children aged 2 and over, nursery schools and classes and ELBs are expected to follow broadly the same procedures for identifying and meeting young children's special educational needs as are recommended for children of compulsory school age. For very young children the Code indicates that a home-based learning programme may provide the most appropriate help.

1.5 Assessment of children under 2 need not follow the statutory procedures. The Code indicates that statements of special educational need will be rare for children under 2 and procedures are not specified in legislation.

1.6 The Code of Practice does not refer by name to Autism, Autistic Spectrum Disorders or Asperger syndrome, but it does recommend that ELBs should, when considering whether a statutory assessment is required, seek evidence of severely impaired social interaction, or a significantly restricted repertoire of activities, interests and imaginative development, and evidence that the child's communication difficulties impede the development of purposeful relationships.

1.7 A diagnosis of an Autistic Spectrum Disorder, or any other condition, does not automatically result in an ELB conducting a statutory assessment or making a statement of special educational needs. The Code of Practice indicates that the ELB should arrange a statutory assessment where there is evidence that the child's difficulties: are significant and/or complex; have not responded to relevant and purposeful measures taken by the school and external specialists; and may call for special educational provision which cannot reasonably be provided within the resources normally available to mainstream schools in the area.

1.8 The Code of Practice (para 4.34) indicates that ELBs have a qualified duty to secure that children with statements are educated in mainstream schools provided that 3 conditions are met. The placement must be appropriate to the child's needs, while also compatible with the interests of children already in the school and with the efficient use of the ELB's resources. Parental preferences must also be taken into consideration, provided these preference are not in conflict with the 3 conditions described above. These 3 conditions also govern the choice of which special school a child may attend.

1.9 The Code of Practice indicates (para 4.47) that an ELB may arrange for all or part of a child's special education to be made otherwise than at school, but in all such cases the ELB must be satisfied that the interests of the child require the arrangements to be made and that they are compatible with the efficient use of resources. The legal basis for this guidance is provided in Article 10 of the Education (Northern Ireland) Order 1996. These obligations on the ELB are of particular relevance in the case of young autistic children as parents sometimes ask their ELB to arrange for some or all of a child's education to be provided at home through specialist programmes which may be very costly. Article 10 also allows ELBs to arrange special educational provision in privately-run schools, ie in non-grant-aided schools, but again the ELB must be satisfied that the interests of the child require the arrangements to be made and the arrangements must be compatible with the efficient use of resources. The Task Group is aware of a very small number of instances in which ELBs have arranged for children on the Autistic Spectrum to attend private specialist residential schools.

1.10 The Education (Northern Ireland) Order 1996 also allows parents who are not satisfied with the manner in which the ELB is dealing with their child's special educational needs to appeal to the Special Educational Needs Tribunal. A small number of appeals have been made in Northern Ireland by parents of children on the Autistic Spectrum.

MEMBERSHIP OF THE TASK GROUP

1.11 The Task Group was chaired by the Principal Educational Psychologist of the Belfast Education and Library Board. In preliminary discussions with Department of Education it was agreed that the Group should be made up of educational practitioners with an interest in autism and representatives of voluntary organisations. Two inspectors would participate, one from each of the Departments of Education in Northern Ireland and in the Republic of Ireland. The inspectors would facilitate liaison between the Task Group and the Task Force on Autism which had been established in the Republic. In the interests of ease of convening meetings and progressing the work, it was decided to keep the North's Task Group small, but that members would consult widely with a variety of professionals and parents across the 5 Education and Library Board areas. The membership of the Group was as follows:

- Martin J Clarke (Chair) Principal Educational Psychologist, Belfast Education and Library Board;
- Jane Houlihan (Secretary) Assistant Advisory Officer (Special Education), Belfast Education and Library Board;
- Dr John Hunter, Inspector, Education and Training Inspectorate, Northern Ireland;
- Brendan Murphy, Inspector, Department of Education and Science, Dublin;
- Gillian Boyd, Principal, Glenveagh School, Belfast;
- Lorraine Scott, Assistant Advisory Officer (Autistic Spectrum Disorders), Southern Education and Library Board;

- Brian Campbell, Educational Psychologist, Western Education and Library Board;
- Carole Adair, Educational Psychologist, North Eastern Education and Library Board;
- Joe Carleton, Occupational Psychologist, Department for Employment and Learning;
- Joanne Douglas, Educational Psychologist, National Autistic Society;
- Arlene Cassidy, Director, Parents and Professionals and Autism (PAPA).

During course of the Group's work, Brian Campbell was replaced by Carol Adair and Joanne Douglas ceased to work for the National Autistic Society and could no longer represent the Society on the Group.

TERMS OF REFERENCE

1.12 The Department of Education proposed the following terms of reference to the Task Group:

- to advise the Department of Education on the range of provision for children with autism across the Education and Library Boards;
- to identify training needs, training opportunities and indicators of good practice for teachers and, as appropriate, parents;
- to recommend a model of provision to promote consistency of approach to identification and service delivery across all Boards;
- to produce a report to the Department on the above, by 31 March 2001; and, concurrently;

- to inform and learn from ongoing work on autism provision on a North-South basis; and

- to contribute as appropriate to the compilation of reports to Ministers of the North-South Ministerial Council. (Since the education sector of the North-South Ministerial Council did not meet again during the life of the Task Group, this element of the terms of reference was not brought into effect.)

1.13 Children with autism require services which are provided by members of many different professions working in a variety of agencies and their need for such services continues into their adult life. The Group has therefore made recommendations which will not only be of relevance to the Department of Education (DE), but also to the Department of Health, Social Services and Public Safety (DHSSPS) and the Department for Employment and Learning (DEL).

METHODS OF INFORMATION GATHERING AND CONSULTATION

1.14 Individual members of the Task Group took responsibility for gathering information of relevance to different chapters of the report using a variety of methods and sources including the following:

- interviews with individual teachers in schools and other professionals such as speech and language therapists;

- questionnaires completed by board officers and school principals;

- submissions from PAPA parents' groups, and the PEAT group (Parents' Education as Autism Therapists);

- attending meetings of parents' groups;

- writing to professionals in Trusts and Boards asking them to comment on the accuracy of drafted sections of the report and to make other comments in writing to the Group;

- inviting expert speakers to address the Group;
- reading Education and Training Inspectorate reports;
- reading a wide range of published research, review articles, and relevant pieces of legislation and the Code of Practice (Special Educational Needs);
- meeting with the South's Task Force on Autism and discussion with the liaison inspectors about the work of the Task Force.

1.15 A full list of those who were consulted is provided in the Appendices. A references section also identifies the publications which are referred to in the report.

STRUCTURE OF THE REPORT

1.16 The report is divided into 11 chapters.

Chapter 1: Introduction to the Report of the Task Group on Autism

Chapter 2: Overview of Autistic Spectrum Disorders: Implications for Educational Provision

The essential features of Autistic Spectrum Disorders (ASD) are described, broad implications are drawn and recommendations made about how educationalists should respond to these.

Chapter 3: Approaches, Perspectives and Debates: Implications for Educational Provision

The most common approaches for meeting the needs of children and young people with ASD are described along with some associated debates and controversies. Implications are drawn and recommendations are made.

Chapter 4: Prevalence and Incidence: International; Northern Ireland

A review of international research on prevalence of ASD is presented along with a survey of prevalence rates in Northern Ireland conducted in the academic year 2000-2001. The Task Group conducted this survey because the ASD prevalence rate in Northern Ireland was not known, yet it was commonly believed that the rate was rising rapidly, and that there were significant variations between boards and across age groups.

Chapter 5: Diagnostic Services and Early Intervention

The consensus among experts on ASD is that early diagnosis and support is of great importance if the best outcome for the child is to be achieved. A survey of diagnostic services across the 5 ELB areas is presented along with a survey of the post-diagnosis follow-up arrangements for children and their families. This chapter focuses primarily on family based support for young children before they begin to attend pre-school or nursery provision. The Task Group makes recommendations for improvement of services.

Chapter 6: Nursery and Pre-School Provision

Frequently children with ASD have had a diagnosis before they begin to attend nursery or pre-school, and support services to these educational provisions are developing. A survey of these support services is presented, good practice noted, and recommendations are made for improvement.

Chapter 7: Primary Provision

Most children known to have ASD are currently being educated in primary schools including special units or schools for children with moderate learning difficulties, and other difficulties. A survey of the support provided is presented, good practice noted, and recommendations are made for improvement.

Chapter 8: Post-Primary Provision

Relatively few children known to have ASD are currently being educated in the post-primary sector, including special units or schools for children with moderate learning difficulties and other difficulties. The survey of prevalence (Chapter 4) indicates that the number will rise rapidly within the next few years. The needs of these children are likely to be different from those of younger children so the Task Group presents a survey of support provided, notes good practice and makes recommendations for improvement.

Chapter 9: Provision for Children with ASD and Severe Learning Difficulties

The needs of children with ASD in combination with Severe Learning Difficulties (SLD) are likely to be different from those of children with ASD alone. A survey of support for children attending SLD schools is presented, good practice noted, and recommendations for improvement are made.

Chapter 10: Provision for Children with ASD and Challenging Behaviour

Children with ASD behave in ways which are sometimes difficult to understand and in extreme cases can be dangerous or disruptive to others in school and at home. The Task Group considers the challenge presented by extreme behavioural problems and makes recommendations for provision.

Chapter 11: Further and Higher Education, Training and Employment

Providers of Further and Higher Education and of training and employment are aware of only a small number of young people with a diagnosis of ASD. The survey of prevalence (Chapter 4) indicates that this number will increase over the next few years. The Task Group presents a survey of the services currently available for young people with special needs, notes good practice, and recommends improvements.

Appendices	**List of Consultees**
	Glossary
	References

CHAPTER 2

OVERVIEW OF AUTISTIC SPECTRUM DISORDERS: IMPLICATIONS FOR EDUCATIONAL PROVISION

This chapter outlines the nature of Autistic Spectrum Disorders and the general implications for education provision.

WHAT IS AUTISM?

2.1 An Autistic Spectrum Disorder is a complex developmental disability that essentially affects the way a person communicates and relates to people. The term ‘autistic spectrum’ is often used because the condition varies from person to person. Asperger syndrome is a condition at the more able end of the spectrum. At the ‘less able’ end of the spectrum is Kanner’s syndrome, sometimes referred to as ‘classic autism’.

2.2 **‘Me and Asperger Syndrome**

> ***When I was 8 I found out about Asperger Syndrome or AS and since then my life has changed completely. Before that life was very hard for me. Life was depressing.***
>
> ***I always knew I was different and that I wasn’t like other children. It’s hard to say exactly how I knew. I detected some differences and I felt that things were not the same for me as for other children. Other children seemed to behave differently, but I didn’t know why. At that time, although I felt different I felt normal about being different. I thought I was the normal one and that***

> ***it was the other people who were different, not me. Which is a perfectly feasible way of thinking'.***
> ***(Kenneth Hall, Age 10, from his own book "Asperger Syndrome, the Universe and Everything",***
> ***Jessica Kingsley Publishers, December 2000).***

> ***'He wandered about smiling, making stereotyped movements with his fingers, crossing them about in the air. He shook his head from side to side, whispering or humming the same 3-note tune. He spun with great pleasure anything he could seize upon to spin… When taken into a room he completely disregarded the people and instantly went for objects, preferably those that could be spun… He angrily shoved away the hand that was in his way or the foot that stepped on one of his blocks…' (Kanner 1943)***

2.3 The condition and behaviour patterns associated with "early infantile autism" were first described by child psychiatrist, Leo Kanner (1943). According to Kanner, the main features of this condition include severe social impairment, communication, rigidity of thought processes and ritualistic patterns of behaviour. At much the same time in Europe, a very similar group of children were described by Hans Asperger (1944) and characterised by their odd, naïve, and inappropriate social behaviour, long-winded pedantic speech, poor non-verbal communication, narrow interests and poor motor co-ordination skills. They were also described as having difficulty in applying skills in a flexible, functional way. The work of both Leo Kanner (1943) and Hans Asperger (1944) form the basis of our understanding of Autistic Spectrum Disorders today. While there has been much debate around the definition of autism, and Asperger syndrome in particular, it is now generally accepted that both autism and Asperger syndrome fall within a broader group of social and communication disorders, commonly known as Autistic Spectrum Disorders (ASD).

2.4 One of the most significant contributions to the clinical understanding of autism as a spectrum disorder, has been that of Lorna Wing (1979). After conducting an intensive epidemiological study, Wing concluded that social impairment is a disorder of development and that the different manifestations, whether or not they are named as syndromes, are all part of a ‘spectrum’ of related disorders. Wing found that there were 3 areas of development associated with this social impairment, forming a cluster of features that provide diagnostic criteria for the identification of autism. This cluster is referred to as the triad of impairments (see Figure 1 overleaf) (Wing and Gould, 1979):

- impairment of Social Interaction;
- impairment of Social Communication;
- impairment of Social Understanding and Imagination.

Figure 1

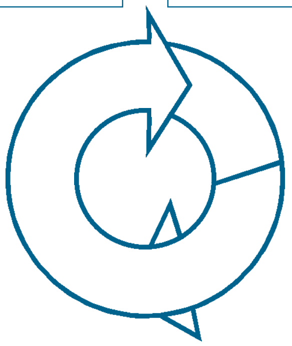
Wing's Triad of Impairments

Impairment of Social Relationships

Impaired, deviant and extremely delayed social development - especially interpersonal development. The variation may be from very cut off and aloof, to passive, active but odd, or over-formal social skills.

Impairment of Social Communication

Impaired and deviant language and communication - verbal and non-verbal. Deviant semantic and pragmatic aspects of language, ranging from lack of formal communication system, expressing only own needs, echolalic and repetitive, factual and literal, pedantic.



Impairment of Imagination and Thought

Rigidity of thought and behaviour and impoverished social imagination, ranging from inability to play imaginatively with toys or other children, involved in repetitive stereotyped activities, difficulties in understanding abstract concepts such as feelings and emotions.

2.5 Autism is now generally recognised as a complex developmental disorder of lifelong duration which affects the individual in varying degrees of severity. The concept of a spectrum reflects the varying nature of each individual's autism experience which does not fit neatly into Kanner's or Asperger's descriptions. The "autistic spectrum" is preferred to the term "pervasive developmental disorders", first used in the 1980s, but currently found confusing as most children's profiles of skills and impairments are usually patchy rather than pervasive. The term "Autistic Spectrum Disorders" (ASD) is used in most contexts in this report.

2.6 Individuals within the autistic spectrum differ in how severely they are impaired in each of the triad areas - some will have significant difficulties in all areas, while for others, their difficulties may appear to be quite subtle. Some people with the condition may also have accompanying learning difficulties, while others are much more able, with average or above average intelligence (Wing, 1996). Similarly, linguistic skills range from those who display complex, grammatically correct speech to those who have none. Despite all the wide-ranging differences, everyone with the condition has difficulty with social interaction, social communication and social imagination. In addition, there are variable features which may be displayed by some, but not all, individuals with autistic spectrum disorders. These include specific language difficulties, eating problems, sensitivity to sound, touch, smell or taste, fine and gross motor difficulties, attention difficulties, behaviour problems and/or special skills (Wing, 1996).

2.7 Sadly, there is no known cure for autism but appropriate support and education in the early years can greatly improve later functioning, and can help those who are affected to live their lives with as much dignity and independence as possible. The parents of children with ASD are faced with numerous problems, mostly resulting from the social, communicative or obsessional difficulties that are fundamental to the disorder.

2.8 Reviews of epidemiological studies using various definitions of classic autism provide rates ranging from 3.3 to 16.0 per 10,000. There are relatively few studies which include the broader definition of Asperger syndrome. The UK National Autistic Society's latest figure for the prevalence of the full range of Autistic Spectrum Disorders is 91 people in every 10,000 (Approx. 1 per 100). These figures include people at the more able end of the spectrum who may not need specialist services and support but will still benefit from early recognition and sympathetic understanding of their special needs and unusual patterns of skill. Figures for Northern Ireland indicate that nearly 1000 children and young people have been identified as having an ASD. While prevalence and incidence rates will be considered in more detail in Chapter 4, it is significant to record at this stage that many professionals report an increase in the number of individuals referred for diagnosis and assessment.

2.9 Two questions arise: is there a genuine increase in the numbers of individuals presenting themselves with the condition or is there another explanation? And where, on the autistic spectrum, are the numbers increasing? It is difficult to give definite answers, as health, social and educational services do not usually define those with ASD as a distinct grouping. Additionally, those with an ASD can be considered by different government departments according to their age, ability and home area, making it difficult for any one department or professional to have access to information on the total population with autism. It is also notable that diagnostic tools vary across the various professionals.

2.10 ASD can be caused by a variety of conditions that affect brain development and occur before, during and after birth. The conditions include, for example, maternal rubella, tuberous sclerosis, anoxia and encephalitis; fragile X chromosomal abnormality is found in a small proportion of children with ASD. Genetic factors are important in cases though the sites of the relevant genes have not yet been identified. Recent concerns have been raised about vaccinations as being a possible cause (Wakefield, 2000); however, the Medical Research Council (April 2000) concludes that there is no new evidence to suggest a causal link between measles, mumps and rubella (MMR) vaccination and autism. Further research by Ross (2000) found that the rate of incidence is no higher among vaccinated children. In a further commentary, Frank De Stephano and Robert Chen of the United States Center for Infectious Disease Control and Prevention note that autism has a strong genetic component and that the associated defects probably occur prior to birth although diagnosis only happens later. While the debate remains, it is beyond the scope of this report to comment further.

2.11 As indicated above, the set of 3 core components, known as Wing's triad, is the basis for the diagnosis of autism (Rutter and Schloper 1987). Health professionals, since the late 1970s, use 2 main classification systems to diagnose autism: the International Classification of Diseases (ICD-10) and DSM-IV. Asperger syndrome, by contrast, did not reach the ICD or the DSM classifications until the 1990s, and there is still some confusion over the diagnostic criteria as to whether it differs from high functioning autism. DSM-IV, for instance, excludes the diagnosis of Asperger syndrome if the child also fulfills the criteria for autism, whereas ICD-10 is more equivocal. Within the areas identified by ICD, however, there is huge variability. As with all psychiatric diagnostic criteria, the criteria are more effective when used by a trained and experienced clinician as part of the overall evaluation of data rather than as a checklist for autism.

2.12 All people with autism have their individual characteristics and personality. The condition may, therefore, appear different in the same child at different ages, and with different cognitive levels in children. Because of this variability and also because it is difficult to disentangle problems in social interaction, communication and ritualistic or obsessive behaviours, it is best to use tools or instruments that specifically test for the presence of autistic symptomatology (Howlin, 1998). In clinical practice, it is common for individuals to exhibit a mixture of features of classic autism and Asperger syndrome. It is more useful, when diagnosing for educational purposes, to indicate levels of ability than to identify children into theoretical diagnostic subgroups. Perhaps of equal importance is the need to clarify diagnostic procedures to secure early diagnosis, which is now well regarded as the most significant variable in a positive prognosis (Lovaas, 1987; Mesibov, 1997). It is the Task Group's conclusion that early and precise diagnosis is crucial to educational planning and outcomes; this issue is considered in Chapter 5 in some detail.

2.13 ASD can occur in association with other physical or psychological disabilities, including cerebral palsy, Down's syndrome or other chromosomal disorders. ASD often co-exists with dyslexia, language disorders, general learning difficulties and visual or hearing impairment. Among adolescents and adults, psychiatric illnesses, including anxiety and depression, can complicate the impact of the ASD. For diagnostic purposes, it is important to identify other co-mordant conditions as they may impinge on the child's learning and have important implications for treatment and prognosis.

2.14 The whole nature of autism …is that every kind of impairment in autism has links with every other impairment in the syndrome. They all overflow into and pervade each other, and it is indeed the interaction between the parts of the syndrome which is most characteristic of autism (Newson, 1997).

2.15 Diagnosis, as a consequence, should include an accurate and comprehensive assessment from which appropriate educational and health intervention can be developed.

IMPLICATIONS FOR EDUCATIONAL PROVISION

2.16 Education remains the one treatment approach with the best 'track record' for dealing with the difficulties associated with autism. It is not just a matter of 'access' to education as a statutory right for children with autism, but about how education can have a central role in 'remediating' the effects of autism (not curing it) and improving the quality of life for individuals throughout their life span (Jordan, 1997).

2.17 The Warnock Report (1978) and the subsequent Education Act 1981, the Education (Northern Ireland) Order 1996, and the Special Educational Needs Code of Practice (1998) identify the general goals of education as the same for all children, irrespective of ability or condition. The challenge for educationalists is to bring educational goals into harmony with the individual needs of the child. The individual needs of a child with an ASD must therefore be identified, and responded to, in any educational programme in relation to the curriculum content, the teaching strategies and approaches used, and the settings where the educational programmes are to be carried out and applied. In order to modify the impact of autism and to ensure the effective educational development of children with ASD, it is crucial to understand the nature of autism and the impact on the individual.

2.18 The Task Group contends that understanding the nature of autism provides an effective basis on which practical approaches can be constructed.

2.19 The ASD impairments will affect each individual differently but they all will experience difficulties in relation to:

- communication;
- social interaction;
- learning;
- behaviour;
- sensory stimuli;
- anxiety and stress[1].

2.20 Individuals with autism differ as much from one another as they do from their non-autistic peers. Individuals with ASD share the basic impairments. However, each impairment will show contrasting variation in depth, and the interplay with the other impairments will determine the type of educational programme necessary to secure progress.

Communication Impairments

2.21 Many children with ASD do not acquire speech; some remain silent while others use speech in repetitive fashion and mostly without purpose. Those children with higher functioning autism or Asperger syndrome tend to have a highly developed vocabulary but have problems with the use and understanding of language, particularly in

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[1] ***(Teaching students with Autism: A Resource Guide for Schools. British Columbia, Ministry of Education, Special Programs Branch 2000)***

the area of interpersonal communication. Language difficulties may include:

- lack of appreciation of the social meaning or function of communication: in particular, the tendency to talk at rather than to others;
- poor understanding/use of speech, gesture, facial expression, bodily posture or voice pitch or intonation;
- literal understanding/use of words;
- variation in the use of speech from an absence of speech to a repetitive use of words and/or muddling of the sequence of words;
- lack of eye contact;
- monotone quality of voice;
- restricted vocabulary;
- undue repetition of a topic;
- inability to maintain a conversation.

2.22 In Northern Ireland, there is a scarcity of speech and language therapists and the indications are that this situation will continue.

2.23 Accordingly, the Task Group findings indicate the need to:

- ensure comprehensive speech and language assessment and input to the overall intervention programme for the child with ASD;
- prioritise communication within an individual programme;
- ensure that speech and language therapists are trained to address the specific needs of children with ASD;

- secure sufficient speech and language therapists to meet the needs of the ASD population in Northern Ireland.

Social Interaction

2.24 Individuals with ASD vary in their abilities to mix socially and consequently to benefit from social interactions; in particular, they have difficulty establishing relationships or friendships. It has been theorised that individuals with ASD are not able to understand others' perspectives or indeed to understand that others have a perspective which can differ from their own. As a consequence, individuals with ASD tend to remain aloof, passive or 'active but odd' in their social behaviour and have a tendency to play in unusual ways and without imagination. Parents of children with ASD report this as an area of most concern and are often at variance with teachers in this regard. (ETI Asperger Survey 2000)

2.25 The implications for educational intervention include the need for a social skills curriculum as a core element in developing appropriate programmes for promoting appropriate social behaviour. Individuals with ASD do not develop social skills naturally or incidentally.

2.26 The Task Group considers that it is crucial to include social skills training in all intervention programmes for children and young people with ASD.

Learning

2.27 ASD span the intellectual spectrum and are frequently associated with learning difficulties. Individuals with ASD are known to have deficits in many cognitive functions yet not all functions are equally affected. Current research identifies the following common learning difficulties:

- paying appropriate attention to or focusing consistently on tasks or activities;

- thinking and reasoning abstractly;

- planning, organising and solving problems;
- understanding language and expressing thoughts, particularly feelings and emotions.

2.28 As a consequence a child with an ASD may experience a variety of problems including generalising learning, literal understanding of language and an inability to “join in” with peers in activities such as play or team games.

2.29 ASD individuals demonstrate huge variation in their learning profiles; some may excel at visual-spatial tasks and recalling simple information; they learn and remember best information presented in visual form but have problems comprehending oral or written information. Connor (1999) suggests the need for teachers and others who provide educational intervention to ensure provision reflects:

- a visual structure and constant routine;
- an individual approach to intervention;
- a sensitivity to the child’s autism and anxiety level;
- a simple and clear use of language.

2.30 The Task Group considers that individuals with ASD have a mixed pattern of learning strengths and weaknesses which must be identified to ensure effective differentiation of provision.

Behaviour

2.31 Individuals with ASD often display unusual behavioural characteristics. The individual with an ASD frequently exhibits stereotyped behaviours, including a resistance to change and a distinct insistence on sameness. Other characteristic behaviours include:

- restricted interests and preoccupations with particular objects or movements;

- repetitive mannerisms eg hand-flapping or spinning objects;
- unusual reactions to certain situations or stimuli.

2.32 A minority of children with ASD display extremely challenging or aggressive behaviour (see Chapter 10).

2.33 Intervention should focus on the development of strategies which structure the environment to provide the child with a sense of security conducive to learning appropriate behaviours in a range of settings.

Sensory Stimulation

2.34 Individuals with ASD respond differently to sensory stimulation; the responses vary from restrained sensitivity to over-sensitivity and may fluctuate unpredictably. Some children with ASD do not like being touched or may over-react to certain textures, including food. Some may find certain sounds or smells, innocuous to others, quite painful; other children with ASD may use smell to explore their surroundings, cover their eyes or stare for lengthy periods when they see shiny objects. Some children with ASD may be clumsy, dyspraxic or engage in constant spinning beyond that which others can tolerate.

2.35 The implications for intervention include the need for teachers to understand the sensory difficulties children may experience as a consequence of their autism, and to set appropriate targets to address each child's sensory needs.

Anxiety and Stress

2.36 Parents and teachers often report on their children's stress and anxiety, ranging from withdrawal to a bedroom to an outburst of emotion on return from school. At its worst, teenagers, particularly those with Asperger syndrome, experience panic attacks and extreme emotional anxiety and fear. For some individuals the consequences can be increasing isolation, a lack of identity of self and a lack of ability to integrate emotions and consequences.

2.37 Intervention programmes need to address the issue of anxiety and stress as a normal consequence of ASD. Appropriate support must be provided to counsel the individual with ASD, to enable him or her to cope with and manage difficult situations. Access to expertise on ASD within the mental health programme of care provided by Health and Social Services should be an integral part of the provision made for the individual.

CHAPTER 2

OVERVIEW OF AUTISTIC SPECTRUM DISORDERS: IMPLICATIONS FOR EDUCATIONAL PROVISION

RECOMMENDATIONS

In this chapter the Task Group has noted many implications of ASD for educational provision. The Group makes the following broad recommendations about how these implications should be taken into account by those who are engaged in planning and developing provision, in providing training for staff, and in teaching children and young people with ASD. Some of these recommendations are expressed in greater detail in later chapters.

Recommendation 2(i)

Educationalists should recognise that education has a central role in 'remediating' the effects of ASD and improving the quality of life for individuals throughout their lifespan.

Recommendation 2(ii)

The central factor in educating an individual with ASD is to understand the nature of the disorder in order to facilitate learning and social inclusion: teachers, parents and others planning educational programmes for individuals with ASD should have an understanding of ASD.

Recommendation 2(iii)

Early diagnosis should be available and should include an accurate and comprehensive assessment from which appropriate educational and health interventions are developed, and should also include identification of co-mordant conditions.

Recommendation 2(iv)

Teachers and others contributing to programmes should be provided with relevant information arising from the diagnostic assessment process.

Recommendation 2(v)

Comprehensive speech and language assessment and input to the programme is essential: the deployment and training of speech and language therapists should reflect this.

Recommendation 2(vi)

Social skills training should be provided as an essential element of intervention programmes for children and young people with ASD.

Recommendation 2(vii)

The learning strengths and weaknesses of children and young people should be identified to ensure effective differentiation of provision: an emphasis on visual communication, simple and clear use of language and constant routine are of particular value when teaching children with ASD.

Recommendation 2(viii)

Interventions should focus on the development of strategies which structure the environment to provide the child with a sense of security conducive to learning appropriate behaviours in a range of settings.

Recommendation 2(ix)

Teachers and others should understand the sensory difficulties which children may experience as a consequence of ASD and set appropriate targets to address each child's sensory needs.

Recommendation 2(x)

Intervention programmes should address the issue of anxiety and stress as a normal consequence of ASD.

CHAPTER 3

APPROACHES, PERSPECTIVES AND DEBATES: IMPLICATIONS FOR EDUCATIONAL PROVISION

This chapter presents the Task Group's review of the main approaches to intervention and considers the implications for the development of effective educational provision.

INTRODUCTION

3.1 Autism is a subject which provokes much debate within many professions, parent groups and voluntary bodies, and in the popular and specialist media. This chapter will focus on issues which are of particular relevance to the development of educational policy in respect of ASD provision. These are:

- approaches to treatment and intervention for children with ASD including the issue of intensity of provision;
- inclusion;
- the role of educationalists in diagnosis and intervention; implications for educational provision.

3.2 In spite of the significant improvement in ASD provision over the past 10 years, there are a number of limitations and difficulties in the current provision. These are highlighted below and considered further in the following chapters. Current limitations indicate that:

- there is more to be done to ensure effective provision for children and young people with autism;
- there remain unresolved difficulties among ELBs and professionals concerning methodologies and approaches which make it imperative that there are

clear policy directives to inform practice and promote consistency across the boards;

- there is a need to focus on training professionals and others who work closely with individuals with ASD;
- there is a need to work more closely with parents and parent bodies to secure their active participation in the planning, management, delivery and evaluation of services and to reassure them that statutory provision will meet their children's needs.

3.3 Exclusive adherence to one method of support for children with ASD is rare in Northern Ireland. Frequently, the child and the family will be receiving support from a number of people from different professional backgrounds such as medicine, speech and language therapy, occupational therapy, social services, teaching, psychology and voluntary organisations. Usually this support is not provided within the context of a co-ordinated programme which is designed specifically for children with ASD, although both PAPA and Barnardo's have established small-scale early intervention schemes (the Keyhole Project and the Forward Steps pre-school service). However, two of the major approaches have been the subject of much debate and discussion locally and are described below in some detail. The TEACCH programme (Treatment and Education of Autistic and related Communications-Handicapped Children) is very widely promulgated in Northern Ireland, and many aspects of the programme are employed, along with other methods, in special and mainstream schools for pupils of all ages. Applied Behavioural Analysis (ABA), sometimes referred to as the Lovaas approach, focuses mainly on early intervention, especially during the pre-school years. It is the preferred approach for a small but significant number of parents. The latter approach has given rise to disagreements between parents and boards, and some parents have appealed to the Special Educational Needs Tribunal in order to have the boards fund Lovaas-type programmes for their children. The chapter will also comment on other commonly used methodologies, including the Picture Exchange Communication System which is gaining favour here, and will provide an overview of Keyhole and Forward Steps which are locally-developed projects in the early stages of implementation. Reference is made to relevant literature and submissions to the Task Group. To conclude the chapter the Task Group sets out basic principles which should underpin the development of services for children with ASD.

Approaches to Treatment and Intervention for Children with Autistic Spectrum Disorders

3.4 There are many forms of intervention and treatments for children with Autistic Spectrum Disorders, and there is much debate about which of these are effective. Some evaluations of approaches to treatment and intervention for children with ASD distinguish between biological, behavioural and cognitive methods and indicate the relative merits of each. Other evaluations attempt to derive principles or guidance on which evaluations of approaches can be made. It is impractical to comment in detail on the excess of approaches currently being marketed; this review is restricted to comments on the main approaches used here and aims to establish a set of criteria pertinent to Northern Ireland and capable of securing effective provision and choice of approaches. The Task Group is mindful, however, of the need for professionals to update information about other approaches which are being marketed as appropriate ASD interventions. Readers wishing to examine further the variety of approaches in use are referred to Jordan et al (1998), Heflin and Simpson (1998), NFER (2000) and Dawson and Osterling (1997) for more detailed evaluations. It is not the intention of this report to validate particular approaches for the sake of the approaches, but to reason, from a review of the ASD literature and current legislative directives, for a set of guiding principles from which provision, including strategies and appropriate approaches, can be developed. What is of concern to the Task Group is the need to demonstrate to parents of children with ASD that their children have a right to effective educational provision from the point of diagnosis.

3.5 Heflin and Simpson (1998) in their paper discussed 27 approaches available in the United States. The approaches ranged from some where there is little or no evidence to back up claims of effectiveness to some which have been validated by research evidence. In Great Britain, Rita Jordan et al (1998) prepared a report for the Department for Education and Employment in which they reviewed the research on the effectiveness of a wide variety of approaches. Both sets of authors are among many who conclude that no one approach has been proven to be the best approach for all children on the autistic spectrum. Heflin and Simpson put the case as follows:

> ***“We firmly believe that there is not a single method that should be exclusively used to meet the varied needs of children and youth with autism and their families. Indeed, in our opinion, the most effective programs for students with autism are those that incorporate a variety of best practices, including careful evaluation of the effects of various methods.” (Page 207)***

3.6 Rita Jordan et al (1998) stressed that there were methodological weaknesses in all the evaluative studies which she reviewed and these made the results difficult to interpret. As a result, she concluded that

> ***“… there is no really strong evidence that one approach for a child with an ASD is better than another although there is a consensus of findings that early intensive education that involves the parents and includes direct teaching of essential skills with an opportunity for planned integration, can produce significant changes in children with an ASD” (page 7).***

> ***“Science has little to say about the individual case. Autism is so variable and individuals with an ASD so different, that a particular child may benefit from a particular approach at a particular time, regardless of what overall conclusions can be drawn from the research evidence.” (Page 119)***

3.7 Jordan et al conclude,

> ***“an inspired and dedicated teacher (whether this is a professional or a parent) can often succeed against the odds, with whatever approach he or she believes in”***

3.8 Heflin and Simpson point out that federal law permits schools in the United States the choice of methodologies and those schools with well-established methodologies are more likely to succeed in settlements of disputes when they include the following key factors:

- the availability of a developed programme;
- provision of appropriate intensity;
- an emphasis on meaningful outcomes;
- the creation of an individually-tailored programme.

3.9 Discussion of the various methods described below draws substantially on the factors suggested by Heflin and Simpson and, in particular, on the potential of an approach to address the triad of impairments, involve parents and provide opportunities for the child with an ASD to learn alongside non-ASD peers.

3.10 Teaching the child to play with objects and others is a critical component of any early services programme. Additionally, given what is known about normal childhood physical activity facilitating the growth of neurons and consequently improved neurological patterns, structured gross motor activities are vital on a daily basis. Music is often a natural accompaniment to some physical activities, and can provide further sensory input of benefit to the child. Incorporating various kinaesthetic stimuli, eg sand, water, can increase attention to objects and activities, can have a positive effect on the child's development. In summary, all of the things that normally developing children are interested in, and that are offered to them in pre-school programmes, will be of benefit to the child with an ASD. The difference will be in the planning, manner and frequency of delivery of these normal activities.

The TEACCH Approach

3.11 Division TEACCH was founded in 1972 at the University of North Carolina (Lord and Schopler, 1994). It provides services for children and adults with autism and related developmental disorders throughout the State of North Carolina, USA. The programme is a state-wide, community-based programme for children and adults with autism and communication disabilities. TEACCH services are both centre- and outreach-based. There is a demonstration pre-school classroom within the medical school, but other educational services are provided within the school and programmes in the communities within which the children and adults live. A major goal is to provide continuity of services from pre-school to adult life. The TEACCH team has been researching and developing their philosophy and system over the past quarter-century and have identified 7 key principles:

- **Improved Adaptation** - through the 2 strategies of improving skills by means of education and of modifying the environment to accommodate deficits.

- **Parent Collaboration** - parents work with professionals as co-therapists for their children so that techniques can be continued at home.

- **Assessment for Individualised Treatment** - unique educational programmes are designed for all individuals on the basis of regular assessment of abilities.

- **Structured Teaching** - it has been found that children with Autistic Spectrum Disorder benefit more from a structured educational environment than from free approaches.

- **Skill Enhancement** - assessment identifies ‘emerging’ skills and work then focuses upon these. (This approach is also applied to staff and parent training.)

- **Cognitive and Behaviour Therapy** - educational procedures are guided by theories of cognition and behaviour suggesting that difficult behaviour may result from underlying problems in perception and understanding.

- **Generalist Training** - professionals in the TEACCH system are trained as generalists who understand the whole child, and do not specialise as psychologists, speech therapists etc.

3.12 A significant feature of the TEACCH approach is structure which helps the child to feel settled and relaxed. The approach addresses difficulties in organisation, memory, auditory processing and making transitions. There is an emphasis on positive strategies of behaviour management. It is based on an understanding of the difficulties the autistic person may have with communication, social interaction and flexibility. The approach recognises that people with ASD may find it easier to respond to and learn from information which is presented visually. It enables development towards independence but with adults in control, setting goals. It involves the family. TEACCH does not claim to cure autism, or to bring about recovery from autism, but it provides a supportive environment for people with autism whereby many of their difficulties can be circumvented and they can be enabled to live and learn without undue stress and anxiety.

3.13 TEACCH is used with people from all parts of the autistic spectrum and offers continuing support with the primary aim of enabling them to live, as far as possible, as independent members of the community.

3.14 TEACCH in its complete form is not evident in Northern Ireland. However, the 1998-2000 ETI Survey of Provision for Pupils with Severe and Profound Learning Difficulties indicated that, ***"the teachers surveyed were knowledgeable about the principles of TEACCH, and demonstrated considerable practical application of the approaches in their classrooms"*** and ***"In the majority of cases, this has led to successful improvements in the pupils' ability to settle to work, to access the curriculum and to develop routine, positive learning habits"*** (page 16). A recent independent review of the Barnardo's Pre-school Programme which relies heavily on TEACCH concludes that the children involved made substantial improvements on a wide range of motor, perceptual and cognitive processes (Sheehy, 2001).

3.15 The application of TEACCH principles is also evident in many mainstream schools and other special schools and units. Mainstream school teachers are not likely to have had access to a specific training course on TEACCH, but where they have attended a training course on ASD or have been given advice by a specialist advisory teacher, outreach teacher or an educational psychologist they are likely to have been exposed to some TEACCH principles. There is evidence of the effectiveness of the TEACCH approach in improving communication and behaviour and the quality of life of the children with ASD, their carers and teaching and support staff. (Sines et al, 1996; Jordan et al, 1998.) Heflin and Simpson (1998) conclude, ***"TEACCH components of structuring the environment and implementing structured teaching continue to be regarded as instrumental in educational programs for students with autism".*** The approach can be used in the mainstream classroom and with different degrees of intensity.

3.16 TEACCH is not perceived as an exclusive approach. In Northern Ireland professionals often combine TEACCH strategies with other methods such as the Picture Exchange Communication System, Sensory Integration and Music Therapy. PAPA in conjunction with Division TEACCH has facilitated the training of local trainers so that the boards can aim towards becoming self-sufficient with respect to training needs. A number of parents and professionals, in their submissions to the Task Group, indicated their preference for the approach and requested further parental and professional training and implementation of the TEACCH approach.

Applied Behavioural Analysis

3.17 Behavioural interventions for children with autistic spectrum disorders were pioneered in the 1960s by Dr Ivar Lovaas. The proponents of this method suggest that behavioural interventions may help improve the lives of individuals with autism by helping them acquire complex skills such as language, play, self-help and social skills (Lovaas 1981). The principles of the Lovaas programme are described by Dawson and Osterling (1987). They refer to the underlying principle as that of applied behavioural analysis, based on Skinnerian operant conditioning, and to the initial phases of the programme involving intensive, home-based, 1:1 discrete trial training for 40 hours weekly. Lovaas (1987) noted that a 40-hour programme was much more effective than a 10-hour programme, and that the use of “aversives” was also associated with more successful outcomes. Parents receive training and advice so that the programme can be maintained virtually all the child’s waking hours. Parents and other adult helpers share the delivery of the programme. The first year focuses on reducing self-stimulatory or aggressive behaviour, developing compliance, and encouraging imitation and play. In the second year, the emphasis moves to expressive language and interactive play. Access is arranged for the child to pre-school group settings and s/he is taught skills necessary for peer interaction. In the third year emotional expression, pre-academic tasks, and observational learning are emphasised. Aggression or self-stimulatory behaviours are countered by employing strategies such as ignoring, time out and shaping.

3.18 Proponents of ABA cite references to indicate that intensive long-term behavioural treatment has been shown to enhance the intellectual, academic, social, and emotional functioning of children with ASD (Lovaas, 1987; McEachin et al, 1993). Schreibman (2000) claims that treatments based on behavioural methods are enjoying the broadest empirical validation for effectiveness for individuals with autism. Schreibman comments further:

> ***“While it is appreciated that there is no ‘one size fits all’ treatment for children with autism there is as yet no established protocol for relating specific child, family, target behaviour, and treatment variables to individual treatment regimes. Future research needs to include well-conceived and methodologically rigorous investigations allowing for the determination of these important variables”.***

3.19 Svein Eikeseth in a description of the Lovaas programme (1997) identified 9 factors which should be included in such a behaviour-analytic treatment programme:

- **Behavioural Emphasis** - the implementation of scientifically-based procedures.
- **One-to-one Instruction** - instruction should be in 1:1 without distractions.
- **Mainstreaming** - considerable effort should be put into mainstreaming the children with their peers to mirror appropriate behaviours and avoid initial placement in special education.
- **Comprehensiveness** - behavioural analysis should target all areas of deficiency such as language, play, leisure, academic and intellectual skills, self-help skills, and social interaction and friendship.
- **Intensity** - Lovaas (1987) provided a group of 19 autistic children with approximately 40 hours of behavioural treatment per week for 2 or more years. This group is reported to have made significantly greater gains in IQ than those children who received 10 hours or less intervention.
- **Family Participation** - to encourage transfer of language and other skills established in the clinic and special classrooms to home and community settings parents must be involved in the child's treatment and taught to use behavioural techniques.
- **Early Intervention** - Lovaas and colleagues recommend that treatment should begin as early as possible and ideally before the child is 42 months old.
- **Individual Differences** - recognition that there are large individual differences in autistic children's responses to behavioural treatment.

- **Non-aversive Interventions** - contemporary behavioural treatment for children with autistic spectrum disorders does not involve the use of aversive procedures.

3.20 In Northern Ireland, PEAT (Parents' Education as Autism Therapists) advocates the use of Applied Behavioural Analysis. PEAT was established in 1997 with the mission to help children and young people to realize their potential by providing Applied Behavioural Analysis training and support to their parents and carers. A smaller number of parents in Northern Ireland have been supported by LEAP (London Early Autism Project). LEAP is a London-based project, which is affiliated with the Wisconsin Early Autism Project, which in turn is reported to be the largest replication site for Lovaas' research in the world.

3.21 Some parents fund ABA early intervention programmes from their own resources. ABA early intervention programmes vary in cost, but the more intensive programmes can cost well over £20,000 per year per child. The Education and Library Boards remain cautious about supporting intensive ABA early intervention programmes. No board provides an early intervention service which is as intensive as the Lovaas approach, and so when parents seek support for such a service the boards are dependent on external providers and have not taken steps as yet to become self-sufficient in this respect.

3.22 ABA is not only used in programmes for young children. It can be used with older pupils as well. In some local schools for children with Severe Learning Difficulties behaviour strategies from the Institute of Applied Behavioural Analysis are used with apparent success with pupils who exhibit challenging behaviour. The IABA puts particular stress on the avoidance of situations and techniques which may fuel confrontations. Some teachers at other SLD schools have recently received IABA training, which they are now applying with pupils with challenging behaviour, and autism.

3.23 There has been considerable controversy about the Applied Behavioural Analysis approach in Northern Ireland and internationally. Proponents of ABA argue that children with Autistic Spectrum

Disorders should, while they are still very young, be offered up to 40 hours per week of intensive one-to-one home-based behavioural training, because, it is claimed, nearly half of them will, as a result, achieve normal educational and intellectual functioning.

3.24 ***"There is evidence that the longer treatment lasts, the larger the client's gains. Furthermore, in most instances of treatment of autism and pervasive developmental disorders (PDD), relapse will occur when the treatment is terminated. The only exception to that occurs with early and intensive behavioural intervention. A sizable minority of children with autism who started treatment before the age of 4 were successfully mainstreamed and appear recovered." (Lovaas, in Maurice et al 1996, page 242)***

3.25 Lovaas indicates therefore that it is only if the intensive treatment begins when the child is still under 4 years that there is a possibility of recovery. Local professionals who work with young children suggested to Task Group members that they would have grave reservations about being involved in subjecting such young children to such an intense behavioural programme for fear of causing some kind of psychological damage. Some local professionals have also suggested that it may be difficult to remain within guidelines on Child Protection (DE Circular 1999/10) while conducting Lovaas-type programmes. Lovaas-type programmes may involve the therapist working alone with the child, and may include the application of very assertive control techniques, as described for example by Catherine Maurice (1993, p. 240). Lovaas (in Maurice et al 1996 p. 242) reassures readers that aversives are no longer used, and describes an alternative method of dealing with tantrums, in which the therapist or parent is advised to work through the tantrum behaving as though it was not happening, and preparing for the child's assaults by wearing a bathing cap to prevent hair-pulling and wearing heavy covers over arms and legs to minimize damage from bites or kicks. Even though this approach does not involve the administration of any punishments as such, many professionals would feel very uncomfortable about engaging in such a therapy strategy. Parents, however, may take a different perspective. If they have reason to hope that use of such intensive and sometimes tough techniques may bring about permanent "recovery" from autism, they may find it difficult to sympathise with the concerns of professionals, and view their concerns as being trivial in comparison with the potential good long-term outcomes for the child.

3.26 The Task Group considers that while there is such strength of feeling about ABA and the approaches used by some of its proponents to promote its use, there is a danger of losing sight of the needs of the children by focusing too much on winning the methodological argument. As a consequence, some parents and professionals may reject the approach in its entirety even though behavioural methods are viewed by many researchers as an appropriate approach to supporting children with autism.

3.27 Heflin and Simpson (1989) comment,

> ***"ideally the community of reasonable parents and professionals associated with individuals with autism will eventually recognize ABA and discrete trial training as effective tools. We are also hopeful that ABA and discrete trial training will be recognised as being most effective when used in conjunction with other individually determined best practices methods".***

3.28 Jordan et al (1998) report on a study evaluated by Ozonoff and Cathcart, which indicated that, ***"a short (4 month only) TEACCH programme can be effective in improving scores (in conjunction with some ABA schooling) over and above that of a group doing ABA alone."*** Harris and Weiss (1998 quoted in NECTAS Resources Collection on Autism Spectrum Disorders, Whaley and Shaw 1999) make a distinction between early intensive behavioural intervention and "applied behavioural analysis". The authors insist that ABA is essential in the treatment of every child with autism: they list the common features of early interventions as "a rich ratio of adults to children, opportunities for integration with normally developing peers, careful planning for the transition from specialised programmes to more normalised programmes, opportunities for family involvement, and a well developed curriculum". The authors note that these qualities characterise all effective programmes for young children with autism, not just those using an ABA approach. Indeed, the logic of intensive behavioural programming is based on the fact that no single treatment programme is sufficient to optimise treatment outcome (Lovaas 1996). It is not surprising, therefore, that educational providers are unsure of prescribing single approaches and for the most part encourage the use of good practice ASD strategies and supportive therapy provision for inclusion in any programme.

3.29 What is clear is that both parents and professionals require training in behavioural techniques and are fully involved in the implementation of the programme of intervention. Martha Zigler, in her article “One Mother’s Reflection” and in her presentation to the North-South Autism Task Groups (2000) offered 4 emerging themes which are worthy of repeating:

- respect for people with autism has increased greatly;
- writers from a variety of perspectives strongly agree that children must be assessed individually and have their interventions and educational strategies individually tailored;
- most writers agree that what works best in the education of children with autism is a combination of more than one approach, even though one approach is likely to dominate. Several also advocate inclusion of techniques such as sensory integration, speech and language therapy and facilitated communication for older children still not speaking. All agree that a structured environment is necessary and all emphasise the importance of integration with peers as early as possible;
- parents and other family members are seen as critical partners in the education of the children, often doing much of the teaching directly or indirectly.

The Picture Exchange Communication System (PECS)

3.30 The Picture Exchange Communication System (PECS) (Bondy and Frost, 1994) was developed within the Delaware Autistic Programme in the USA and employs the use of pictures to encourage the child's initiation of communication rather than responding to prompts. The aim is to acquire skills in everyday settings that can be developed both at home and in a school. The system is inexpensive, does not require complex materials or manuals or highly skilled training. It can be used in the classroom, the home and a variety of settings. The outcomes reported to date are promising and indicate improvements in communication ability, including the development of speech. Heflin and Simpson (1989) comment:

> ***"PECS is an empirically sound method that has excellent utility in developing communication skills in both non-verbal students with autism and limited communication students with autism."***

The Keyhole Early Intervention Project

3.31 The Keyhole Early Intervention Project is designed for young children aged 2 1/2-3 1/2 years and it operates in one district of Northern Ireland. There are 3 aspects to the project:

- home visiting;
- parent and professionals training;
- parental workshops.

The aims of this eclectic project are to provide parents with training and support to their children to develop appropriate social skills and to enhance their participation in pre-school provision. Families receive 18 home visits over an 11 month period and support to follow an individual family plan. The project is at the early stage of development and is being evaluated by the University of Ulster at Jordanstown. The project has merit in that it involves parents fully at all stages and is underpinned by the belief that the child's developmental and autistic needs are critical to planning effective intervention.

Forward Steps

3.32 The Forward Steps programme developed by Barnardo's is a service for pre-school children with autism operating in the greater Belfast, Bangor and Newtownards areas. The service provides:

- home-based support;
- training for parents;
- short-term assessment;
- pre-school playgroup placement of 12 hours per week;
- inclusion within community services.

The programme based on TEACCH emphasises the visually structured approach and aims to help children to access their local playgroup.

Intensity

3.33 The issue of intensity of approach remains controversial. Strain (2000) claims that there is little evidence that more is better. He suggests the following elements of intervention as more important indicators of success than the total number of hours:

- the quality of teaching;
- the competence of the teachers;
- the degree of continuity across teachers and settings.

3.34 The Task Group contends that decisions about intensity should be made on the basis of multi-disciplinary assessment of the needs of the individual child, his/her well-being and health, and parental choice and resources. A number of writers suggest that the best examples of pre-school provision offer an all-round service, teaching programmes ranging from 15-30 hours weekly and total intervention services ranging from 20-42 hours weekly. While research studies (Lovaas, 1987) indicate that 10 hours is inadequate to effect significant improvements, there is growing evidence that children with ASD improve significantly with 20 hours per week intensive support (Anderson et al, 1987). In their clinical practice guidelines for early intervention, the New York Department of Health recommend that intensive behavioural programmes include a minimum of approximately 20 hours involving systematic use of behavioural teaching techniques, intensive 1:1 direct instruction and extensive parent additional hours of intervention. The guidance indicates that considerations in deciding the intensity and frequency of intervention should include:

- the age of the child;
- the severity of the autism;
- the rate of progress;
- other health considerations;
- tolerance of the child for the intervention;
- family participation.

3.35 What is unquestioned is the need to provide intensive support at an early age, to train both professionals and parents in ASD techniques, including behavioural analysis, and, importantly, to provide support from the point of diagnosis.

3.36 Keogal (2000) points out that programmes which oblige the parents to adapt to the programme requirements increase parental stress, while programmes which adapt to family lifestyles and routines actually decrease family stress and result in greater gains in child communication.

3.37 The Task Group notes that parental stress should be taken into consideration when decisions are made in respect of intervention.

Inclusion

3.38 In Northern Ireland, pupils with ASD may be found in almost every type of mainstream school, special school and special unit, and there are some who are tutored at home because schooling has not been successful. 44% of pupils with ASD attend mainstream schools, 36% attend schools for children with severe learning difficulties and 20% attend other types of special schools and units attached to mainstream schools (see Chapter 4). There is no ASD specialist school or unit, although some classes within SLD schools are specialist ASD classes. A very small number of pupils attend residential ASD specialist schools in England and Scotland.

3.39 While many educationalists and parents will support integration for all pupils with some other forms of learning difficulty, eg all children with moderate learning difficulties, the Task Group have not come across arguments for full integration for all pupils with ASD for all of their period of education. This is perhaps because it is recognised that the mainstream school can, for some ASD pupils, be an extremely stressful place, in part because of the complex social and curricular demands. It has been said that for the autistic person, dealing with people is like doing quadratic equations in your head since so many judgments have to be worked out like problems. In the Survey of Pupils with Asperger Syndrome 1999-2000, conducted by the Education and Training Inspectorate, it was noted for example that:

> ***"A few of the pupils were reported as displaying serious signs of depression, and visits to a clinical psychologist were not uncommon…" and "Parents reported that their children were particularly tired on returning from school, and often were stressed and exhausted. Worry was associated with isolation and lack of friends."***

3.40 It is commonly accepted that these social problems often become more acute as the pupil progresses through the post-primary phase of education. The Task Group also were informed by parents and schools about some pupils exhibiting behaviour which is so challenging that it is not always possible for staff to cope even in the small classes of an SLD school. There is no doubt that many pupils with ASD can and do benefit from mainstream education. It is also clear that if mainstream education is to be successful for more pupils with ASD then there is still much more to be done, at school organisation level and at individual teacher level, to make mainstream schools more inclusive (see Chapters 7 and 8).

Debates about Diagnosis and Intervention

3.41 In Chapter 1 the report highlighted the confusion that may arise as a result of different criteria and different diagnostic instruments being used by different professionals. Diagnosticians also differ in their willingness to diagnose at a very early age. Most would recognise that early diagnosis, if followed by early intervention, is of benefit to the child. On the other hand, the younger the child, the greater the risk of making a misdiagnosis of ASD. There is much variety with respect to which professional disciplines are involved in diagnosis. In Northern Ireland, diagnosis may be carried out by individual professionals, or multi-disciplinary teams. The teams may include psychiatrists, paediatricians, clinical psychologists, speech and language therapists, occupational therapists, and educational psychologists.

3.42 The Warnock Report (1978) encouraged professionals in the field of education to assess and detail the special educational needs of children rather than label them as members of a category. Subsequent legislation abandoned the use of category labels such as ESN (educationally subnormal), Maladjusted, Delicate etc. Many educationalists saw this as a progressive step, and perceived the medical model, ie diagnosing and labelling, to be one which was not appropriate in the field of education. Over time, however, diagnosis and labelling have become commonplace again. These labels are generally applied by medical professionals but it is often educational professionals who are challenged to provide appropriate educational solutions for the problems being experienced by the child. Medical labels are now extensively used in educational contexts, eg Attention Deficit with Hyperactivity Disorder, Dyspraxia, and, of course, Autism, Asperger syndrome, and Autistic Spectrum Disorders (ASD).

3.43 A key reason for the resurgence of diagnostic labels may be that it is frequently easier to argue for extra resources if the child has a named disability of some form, rather than a list of special educational needs. An equally compelling reason is that parents and some people with ASD put value on having a diagnosis. This presents a professional dilemma for those, such as educational psychologists, who are committed to the principles of equity and of making provision according to need rather than making provision according to label. The autistic spectrum is a very wide one. Some children on the spectrum do not need resources beyond what the ordinary mainstream school can provide, and at the other extreme, some can overstretch the resources of even the most generously-provided special school. Most educational psychologists therefore focus on examining the special educational needs of the child and leave the diagnosis and application of the label to health professionals. They would hold the view that the presence of a diagnosis of ASD does not, per se, clarify what, if any, special educational needs the child will have. On the other hand, close examination of the diagnostic criteria for ASD reveals that the condition is one which is very much a psychological disorder related to impairments of perception, thinking, imagining, feeling, and communicating, and this suggests that the main form of “treatment” for the child will be educational in nature. Several SLD school principals expressed the view that schools put a high value on having a thorough educational psychological assessment of children with ASD. It is evident therefore that the educational psychologist must play a major role in the assessment. Philip Whitaker, a Senior Educational Psychologist in Leicestershire, told the Task Group that it was common practice in his Local Education Authority for educational psychologists actually to diagnose ASD. In the same discussion, however, a paediatrician drew attention to the danger of failure to notice additional medical disorders if educational psychologists diagnose outside the context of a thorough paediatric assessment.

3.44 As will be detailed in Chapter 5, the current trend in Northern Ireland and elsewhere is very strongly towards multi-disciplinary and multi-agency diagnosis and assessment, ie various professionals from Health and Social Services and from Education are involved. It is evident that it is generally accepted that the diagnostic label should be used. Even within multi-disciplinary diagnostic clinics, however, practice varies with respect to which professionals actually take responsibility for making the diagnosis. Where educational psychologists are members of a multi-disciplinary team they can provide information about the child, often gathered in another context such as the child’s school, and they may thus assist accurate diagnosis. Even if educational psychologists do not formally take responsibility for diagnosis, they still have a vital role to play in making explicit the special educational needs of the child and thus providing information upon which the child's teacher and others can act when devising the education plan. The Task Group considers that diagnosis should strive to be multi-disciplinary and commends the expansion of such teams across Northern Ireland.

Features of Good Practice

3.45 The Task Group regards as crucial the need to remain abreast of new research and evidenced-based approaches while at the same time offering the best of what current research and parental choice suggest. Strain (1998) recommends that providers require the best available information in order to make effective decisions about intervention. He cites 4 assumptions as a basis for general intervention planning:

- children with autism are children;
- children with autism grow up;
- children with autism have families;
- children with autism live in communities.

3.46 The assumptions appear simplistic but are fundamental to provision and indicate the need for co-operation among the educational, health and social services, providing in holistic fashion for the broader needs of children with autism and their families. Strain further suggests:

- young children with autism should be provided with regular and planned opportunities to interact with typical same-aged peers;
- teaching for young children with autism should be carefully planned, executed and evaluated;
- young children with autism and their families require a level of intervention to match their needs;

- young children with autism and their families require services delivered across many different contexts;
- young children with autism should be provided with a scope and sequence of instruction that covers all areas of developmental needs;
- young children with autism should be enrolled in intervention services as early as possible;
- the challenging behaviour of young children with autism should be addressed with positive, proactive strategies.

3.47 The Task Group endorses the principles set out by Strain and find favour with his comments,

> ***"In such a field of rapidly expanding knowledge, it is the fool who insists upon and speaks with absolute certainty."***
>
> ***"Regrettably, it is also in the nature of a young field to suffer from extravagant claims and the zealous marketing of one size fits all models of intervention."***

3.48 It is evident that there are a number of approaches which result in improvements in skills for children with ASD. What is important for the DE and the ELBs, is to secure effective levels of intervention and appropriate structures to guarantee a range of services which will meet the needs of all children within the autistic spectrum. For most parents in Northern Ireland, the main focus of interest is not on which of the major methods is on offer to them, but on whether they are being offered well co-ordinated support at all. In Northern Ireland the quality and extent of support for the child and family at pre-school level is very variable (see Chapter 5).

3.49 The Task Group findings indicate the need to secure provision which is underpinned by 3 factors:

- the nature of the child's ASD should be central to identifying an individual educational profile upon which provision can be based;
- given the diversity of autistic spectrum disorders, teachers and others involved in teaching provision should be knowledgeable about the nature of autism and the core teaching strategies which reflect this knowledge;
- teachers and others should have a breadth of skills and knowledge of the various strategies and main approaches to securing improvement in the child's long-term prognosis.

3.50 The Task Group notes Dawson and Osterling's (1997) 6 elements which are common to effective intervention programmes:

- curriculum content indicating skills which need to be taught;
- a structured environment which includes strategies for generalised learning;
- predictability and routine to help the child transfer from one activity to another;
- a functional approach analysing and dealing with behaviour;
- plans to enable the child to transfer successfully from pre-school to school setting;
- family involvement as central to the overall programme.

3.51 The Task Group additionally finds the following features identified across the approaches as examples of useful practice:

- an emphasis on 1:1 planning and work;
- staff and parental training;
- an emphasis on communication;
- an emphasis on visual approach;
- an emphasis on developing skills for independence;
- an emphasis on mainstreaming and access to peer curriculum;
- an emphasis on recording and evaluating outcomes.

3.52 In conclusion, the Task Group considers that Strain's recommendations can be adapted to provide ELBs and schools with 6 critical considerations as a legitimate basis for strategic planning of ASD services:

- the significant outcomes of a strategy or approach as value for the input of time, resources and expense;
- the capacity of the strategy or approach to blend with existing provision and current educational principles;
- the potential of the strategy or approach to secure peer curricular access;
- the flexibility of the strategy or approach to address the needs of children across the education phases, including special and mainstream schools;
- the potential of the strategy or approach to involve and accommodate variations in family needs;
- the use of the strategy or approach to meet sibling and family needs.

Implications for Educational Provision

3.53 In this chapter the Task Group has considered debates about the various approaches to meeting the needs of children with ASD, about intensity of provision, about inclusion and about the role of educational psychologists in the processes of diagnosis and assessment of special educational needs.

3.54 Heated debate about which approaches are the most effective is likely to continue but it is clear that early diagnosis and intervention are essential, as is continuing evaluation of the approaches that are used. What is evident is that positive outcomes of programmes are a consequence of intensity and consistency of intervention between the home and the school. Effective provision should address the individual's ASD and provide access to the curriculum of his/her peers.

3.55 In the absence of consensus among researchers that any one approach is for all the children the best, most children with ASD are likely to be in receipt of eclectic forms of support or single forms at different periods in their development. It is important that the approaches offered are evaluated as appropriate to the needs of the child and the family, and the choice of approaches not determined solely by considerations of cost or profit, professional or administrative convenience or demands of advocates for the exclusive use of one particular approach.

3.56 There is consensus that, regardless of method used, the programme on offer to very young children should be very thoroughly designed, characterized by high quality and well co-ordinated teaching and therapy and a high degree of parental involvement of a type which is compatible with the needs of the family. Although such programmes should be intense, intensity should not be equated simply with total number of hours given to the programme. There should be thorough recording of progress made and programmes should be evaluated.

3.57 It is apparent that many pupils with ASD can benefit from mainstream education but many of these will require specialist support, and their teachers will require training. ELBs, in partnership with the voluntary sector, will need to continue to develop support and training services and evaluate their effectiveness.

3.58 It is evident that mainstreaming will not be successful for all pupils with ASD at all stages of their development. ELBs will need to consider the creation of some specialist ASD provision.

3.59 A number of different professions are involved in diagnosis and assessment and in meeting the needs of young children on the spectrum. If intervention is to be successful then multi-disciplinary and multi-agency collaboration is essential.

3.60 The Task Group has not found evidence that there is one simple answer to the question of how to cater for the needs of children with ASD, but, on the contrary, has found evidence that this is a field of endeavour which is developing rapidly and one where a variety of approaches should be encouraged within a framework where the importance of evaluation must be stressed. It would be inappropriate therefore for the Task Group to recommend one particular method. The Group recommends the application of a number of basic principles to underpin the development of services for children with ASD.

CHAPTER 3

APPROACHES, PERSPECTIVES AND DEBATES: IMPLICATIONS FOR EDUCATIONAL PROVISION

RECOMMENDATIONS

Recommendation 3(i)

The Task Group finds preference for no single approach but concludes that single methods by themselves may not address effectively the triad of impairments associated with ASD. The Group concludes that intervention programmes should be child-centred rather than method-centred, and should address the observed and unique needs of the child and any variation in these which occurs over time and across settings and situations.

Recommendation 3(ii)

The Task Group recommends that provision should include strategies and approaches matched to the needs of individual children and delivered in home-based and centre-based settings, as indicated by multi-disciplinary and multi-agency assessments in which parents are fully involved.

Recommendation 3(iii)

The Task Group recommends 7 principles to underpin planning of provision by the Education and Library Boards:

Provision should be:

- ❖ based on current research indicating best practice in respect of achieving meaningful outcomes, providing value for input of time and resources, and promoting independence and inclusion;

- inclusive of a range of methods and approaches which have been shown to be effective or which are judged by those who work with children with ASD to be worthy of evaluation;
- determined by, and regularly reviewed by, multi-disciplinary, multi-agency teams which include parents as well as appropriately trained professionals from the ELBs and HSSBs, and which respond promptly to requests for assessment and intervention;
- reflective of the individual's needs profile, and any changes in these needs over time and across different contexts and reflective of the needs of the family;
- compatible with the Department of Education's pastoral care, including child protection guidelines (Circular 1999/10) and the United Nations Convention on Human Rights (Article 4);
- provided by appropriately trained professionals, and by parents who have also had appropriate training;
- subject to review, evaluation and inspection by the Education and Training Inspectorate.

CHAPTER 4

PREVALENCE AND INCIDENCE: INTERNATIONAL; NORTHERN IRELAND

This chapter investigates the prevalence of Autistic Spectrum Disorders internationally and within Northern Ireland, and the implications for current and future educational provision.

Introduction

4.1 ***"The prevalence of autistic spectrum disorders is a matter of debate". "There are a number of serious problems with calculating prevalence rates and predicting future demand for services. One is that rates and types of diagnosis vary widely between health authorities and also between individual paediatricians and other diagnosticians. Secondly, the definitions and diagnostic criteria for autism are fluid and qualitative in nature, relying primarily on the observation and categorisation of behaviour; thus there is the possibility of both under- and over-diagnosis". Evans, Castle and Barraclough (2001).***

4.2 The above comments provide insight into the difficulties involved in attempting to gather figures relating to the occurrence of Autistic Spectrum Disorder in pre-school children and children of school age. They are particularly pertinent to attempts to establish incidence rates within Northern Ireland.

4.3 It is more than 50 years since Leo Kanner first described his classic autistic syndrome. Since then, the results of research and clinical work have led to the broadening of the concept of autistic disorders. Estimates of prevalence, in consequence, have increased considerably.

Factors Affecting Prevalence Rates

4.4 As the prevalence of ASD is influenced by the criteria used to diagnose it, not only are diagnostic services central to consideration of prevalence rates, so too are factors such as diagnostic criteria and agreement on standardised methods of measurement.

4.5 ASD includes a wide range of individual differences, from individuals who also have a severe learning disability, to those with average and above-average intelligence. All share the triad of difficulties in reciprocal social interaction, communication, and a lack of flexible thinking and behaviour. ASD affects all areas of a child's functioning and has significant implications for the lives of all those affected.

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

4.6 There remains theoretical confusion regarding differential diagnosis, particularly at the extreme ends of the intellectual range. The uncertainty is in relation to the boundaries and the extent of overlap between differing forms of autistic spectrum disorders, and highlights the limitations of current knowledge. The pattern of developmental progress is also variable; children diagnosed with autism in childhood may develop a pattern of abilities and behaviour in adolescence/adulthood that more accurately resembles that of Asperger syndrome/high functioning autism.

> ***'If I were 2 years old today, I would be diagnosed with classic Kanner's Syndrome, because I had delayed abnormal speech development. However, as an adult I would probably be diagnosed as having Asperger syndrome, because I can pass a simple theory of mind test and I have greater cognitive flexibility than a classic Kanner autistic.' (Grandin, 1995)***

4.7 A Diagnostic Scoping Study (1998) carried out jointly by PAPA (Parents and Professionals and Autism), and the University of Ulster highlighted the following issues relating to diagnosis, service provision and education:

- diagnostic services and associated follow-up support provision were variable within Northern Ireland in respect of the quality and effectiveness of diagnostic service provision for people with ASD;
- the length of time taken to obtain a diagnosis remained variable;
- there was a lack of information provided relating to diagnosis or transparent referral routes and follow-up service provision;
- professionals appeared to lack confidence with regard to taking responsibility for making a diagnosis;
- there were few co-ordinated multi-professional approaches to diagnosis;
- there was a need to share the outcome of the diagnosis with members of the multi-professional care/education team;
- there was a need for training, to enhance competence in the assessment and diagnostic process.

4.8 The Task Group on Autism found evidence of continued differential practice both within and across the Education and Library Boards, and Health and Social Services Boards, in relation to the following core areas:

- agreement on diagnostic criteria;
- agreement on standardised assessment tools and techniques;

- types of professionals with responsibility for the assessment and diagnosis of ASD, and the operation or otherwise of multi-disciplinary clinics;
- levels of awareness of ASD and training for professionals;
- availability of early intervention for very young children with ASD;
- resources for children with ASD - their availability at Stage 3 or Stage 5 of the Special Educational Needs Code of Practice;
- availability of in-service training for teaching staff to develop within-school provision;
- availability of specialist ELB advisory/support officers.

4.9 All such factors render the process of collecting valid and reliable data relating to incidence rates of Autistic Spectrum Disorder within Northern Ireland extremely problematic.

Epidemiological Studies
National and International (1963-1995)

4.10 Reviews of epidemiological studies using various definitions of classic autism (Kanner's syndrome) provide prevalence rates ranging from 3.3 to 16.0 per 10,000. UK National Autistic Society's latest figures for the prevalence of the full range of ASD are 91 people in every 10,000 (approx 1 per 100). This results in the estimation that over 500,000 people in the UK have an ASD. These figures include people at the more able end of the spectrum who may not require specialist services and support, but may benefit from early recognition and understanding of their special needs and unusual pattern of skills.

4.11 Twenty years after Kanner first described 'early infantile autism' in 1943, Victor Lotter published the first results of an epidemiological study of children with the behaviour pattern described by Kanner in the former county of Middlesex, which gave an overall prevalence rate of 4.5 per 10,000 children (Lotter, 1966).

4.12 In 1979 Lorna Wing and Judith Gould examined the prevalence of autism, as defined by Leo Kanner, among children known to have special needs in the former London Borough of Camberwell. They found a prevalence in those with IQ under 70 of nearly 5 per 10,000 for this syndrome, closely similar to the rate found by Lotter. In addition to looking at children with Kanner autism, Wing and Gould also identified a larger group of children (about 15 per 10,000) who had impairments of social interaction, communication and imagination, (which they referred to as the 'triad' of impairments), together with a repetitive stereotyped pattern of activities. Although these children did not fit the Kanner criteria, they were identified as being within the broader 'autistic spectrum'. The prevalence rate for the spectrum in all children with special needs in the Camberwell study was found to be approximately 20 in every 10,000 children (Wing and Gould, 1979). Gillberg et al (1986) in Gothenburg, Sweden, found very similar rates in children with learning disabilities.

4.13 There have been a number of other epidemiological studies in different countries examining the prevalence of autism (but not the whole spectrum). The results from these studies range from 3.3 to 16.0 per 10,000. The variability is possibly due to differences in definitions or case-finding methods (Wing, 1993).

4.14 The following are prevalence rates quoted by Lorna Wing (1993) in a review of studies investigating the prevalence of autism. The 4 with the lowest rate of incidence are marked * and the 4 with the highest rate are marked **.

4.15 **Studies Using Kanner's Criteria**

Lotter, 1966,1967, Middlesex - 1 in 2222 (4.5 per 10,000)
Brask, 1972, Aarhus, Denmark - 1 in 2326* (4.3 per 10,000)
Wing and Gould, 1979, Camberwell, London - 1 in 2041 (4.9 per 10,000)
Hoshino et al, 1982, Fukushima-den, Japan - 1 in 2000 (5 per 10,000)

4.16 Studies Using Rutter's Criteria

Bohman et al, 1983, Vasterbotten, Sweden - 1 in 1786 (5.6 per 10,000)
Cialdella and Mamelle, 1989, Rhone - 1 in 926 (10.8 per 10,000)

4.17 Studies Using DSM-III Criteria

Matsuishi et al, 1987, Kurume, Japan - 1 in 645** (15.5 per 10,000)
Tanoue et al, 1988, Ibaraki, Japan - 1 in 725** (13.8 per 10,000)
Sugiyania and Abe, 1989, Nagoya, Japan - 1 in 769** (13 per 10,000)
Burd et al, 1987, North Dakota - 1 in 3030* (3.3 per 10,000)
Ritvo et al, 1989, Utah - 1 in 2500* (4 per 10,000)
Gillberg. 1984, Goteburg region, Sweden - 1 in 2500* (4 per 10,000)
Steffenburg and Gillberg, 1986, Goteburg City - 1 in 1333 (7.5 per 10,000)

4.18 Studies Using DSM-III - Revised Criteria

Bryson et al, 1988, Nova Scotia - 1 in 990 (10 per 10,000)
Gillberg et al, 1991, Goteburg City - 1 in 869 (11.5 per 10,000)

4.19 Study Using Other Criteria

Iahii and Takahashi, 1983, Toyota, Japan - 1 in 625** (16 per 10,000)

4.20 The studies cited so far have identified autistic disorders in children, the great majority of whom have had learning disabilities and special educational needs. However, in 1944, Hans Asperger in Vienna published an account of children with many similarities to Kanner autism but who had abilities, including grammatical language, in the average or superior range.

4.21 In 1993, a study was carried out by Stephan Ehlers and Christopher Gillberg in mainstream schools in Gothenberg to establish the prevalence of Asperger syndrome and other Autistic Spectrum Disorders in children with IQ of 70 or above. They calculated a rate of 36 per 10,000 for those who definitely had Asperger syndrome and another 35 per 10,000 for those with social impairments.

4.22 Sula Wolff (1995), in Edinburgh, studied children of average or high ability who were impaired in their social interaction but who did not have the full triad of impairments. She emphasised the overlap with Asperger syndrome. However, the majority became independent as adults, many married and some displayed exceptional gifts, despite retaining the unusual quality of their social interactions. Wolff argues that such children should be included in the autistic spectrum as they often have a difficult time at school and they need recognition, understanding and acceptance from their parents and teachers. The approach that suits them best is the same as that which is recommended for children with Asperger syndrome and high-functioning autism.

4.23 In her discussion of prevalence, Sula Wolff quotes Ehlers and Gillberg’s study. She considers that their total figure of 71 per 10,000 includes the children she describes.

Recent Epidemiological Studies (1999-2001)

4.24 There is no central register in the UK or in Ireland of everyone who has autism, and as a result the possible number of people with autism in the community must continue to be based on epidemiological surveys (ie studies of distinct and identifiable populations).

4.25 In California, where the rate of autism has risen for the twelfth consecutive year, a study has been initiated to look at possible causes, amongst which are listed maternal age, vaccinations, genetics and environmental factors (The Observer, 17 June 2001). In the USA more generally, the 16th and 21st Annual Reports to Congress on the Individuals with Disabilities Education Act confirm very steep increases in the prevalence of autism between 1992-1993 and 1998-1999. The average increase across 50 states was 338% during this 6-year period. During President Clinton’s visit to Northern Ireland in 2000 one of his educational advisers, addressing the Principal Educational Psychologists Group, indicated that the federal government view was that this increase was more due to changes in diagnostic practices than increases in prevalence of the condition.

4.26 Paul Shattock (2001), director of the Autism Research Unit (ARU) at the University of Sunderland, carried out a study that analysed 6,000 people on the ARU's database. Records give a strong indication of a very large increase in the incidence of autism over the last 10 years.

4.27 Similar results have come from a study of records kept by British GPs (Kaye, J, 2001), analysed by a US team from Boston University. They reported a 7-fold increase in diagnoses of autism in children aged under 12 between 1988 and 1999. The American team postulate a number of factors possibly contributing to the rise in incidence rate including increased awareness of the condition among parents and professionals, changing diagnostic criteria, or environmental factors not yet identified.

4.28 A study reported to estimate the prevalence of autism in a part of Finland (Keilinen, M, Linna, SL, and Moilanen, I, 2000), indicated that ASD may actually be more common than previously believed. General awareness and clinical knowledge of the disorders has increased and the criteria in ICD-10 and the DSM-IV have become more detailed. Diagnostic criteria and methods of gathering information influence prevalence. The Finland study showed the incidence to be lowest - 6.1 per 10,000 - in the oldest age group of 15-18 year old children, and highest - 20.7 per 10,000 - in the age group of 5-7 year olds, when the criteria of ICD-10 and the DSM-IV were used. These were children of whom 50% had a tested IQ above 70, and where the degree of autism (as assessed by the Childhood Autism Rating Scale, CARS) varied from mild autistic features in 8.5% through moderate in 58.5% to severe in 33.0%.

4.29 Tony Attwood examines the reality or otherwise of the reported autism "epidemic" (Attwood, 2000). The article focused primarily on Asperger syndrome. This condition continues to be subsumed within the ASD diagnostic label, therefore, in many cases, Attwood's observations relating to an increase in children and adults being diagnosed as having Asperger syndrome are meaningful also within the context of the increase in ASD incidence rates generally. Attwood suggests that the question of whether or not there is an epidemic of people being diagnosed with ASD (to include Asperger syndrome) is a difficult one to answer. He suggests that the following factors all contribute to an inability to reach conclusions as to why there should be such an increase in diagnosed cases of ASD:

- variable diagnostic criteria;
- overlap with other related conditions such as Attention Deficit with Hyperactivity Disorder (ADHD);
- variability in age of diagnosis;
- lack of adequate recording methods and subsequent lack of data bases.

4.30 A study by Thrower (2000) was carried out to explore the question of whether or not there had been an increase in levels of autism in children under 16, and whether this was indicative of an underlying upward trend. He contacted a range of Health Authorities in England, Wales and Scotland, ELBs in Northern Ireland and Social Services Departments in London. His observations, based upon received responses, highlight the difficulty in reaching conclusions about prevalence rates:

- the variation between estimates in some health areas and actual measured incidence in some other areas is immense, varying at the extremes by up to several hundred-fold;
- the authorities with the most proactive monitoring are those with the highest rates;
- several sources reported a bulge in the figures for pre-school years;
- one health authority carrying out an audit of 3-year old boys across an entire health district over a 2-year period, reported a high rate of prevalence of 1 in 69 (144 per 10,000). It should be noted that since girls were not included in this study and prevalence is much higher among boys the prevalence figure quoted cannot

be taken as an indication of general prevalence among children. Other health authorities/health boards have reported very high rates of prevalence, with rates of well over 1 in 200 for boys (50 per 10,000);

- opinion is divided as to whether it is a matter of better diagnosis or increased prevalence, although a significant number believe there is increased prevalence.

4.31 An article in the Observer (17 June 2001) reported that even cautious researchers have admitted to an "autism epidemic". Incidence rate estimates range from one in 1000 people (10 per 10,000) to one in 110 (91 per 10,000). A Californian study (unnamed) estimated that cases had risen by 30% within a single year. Another study in the West Midlands calculated a yearly increase of 18% in classic autism and 55% rise in cases at the high functioning end of the spectrum. The Observer article indicated that autism incidence figures seem to be rising particularly steeply in Ireland. The difficulty in estimating the extent of the increase in figures is exacerbated by the lack of a register of autistic people, and therefore no comparative data from the past.

4.32 A recent study carried out at the Autism Research Centre, Cambridge University, suggested that as many as 1 in 175 primary school children may suffer from ASD - 11 times higher than previous estimates. This study considered only children with a definite clinical diagnosis. Previous studies had estimated that 5 in every 10,000 children aged between 5 and 11 were autistic, but the new study of children in Cambridgeshire puts the rate at 58 in 10,000. The study established that one in 8 children with special educational needs was suffering from some form of Autistic Spectrum Disorder.

4.33 Results from this study, extrapolated across Great Britain, suggest that 30,000 primary school children and tens of thousands in other age groups may have ASD which may mean that they will need support for the rest of their lives.

4.34 While local education authorities may provide a 'statement' describing a child's learning difficulties and special schooling needs, a diagnosis of the child's underlying ASD is often not recorded. Therefore the Government, Health Authorities and LEAs in England have had no reliable prevalence data upon which to base strategic planning.

4.35 The 11-fold increase described in the Cambridgeshire study has enormous cost implications for Westminster.

4.36 In 2000, a report for The Mental Health Foundation (Jarbrink, K and Knapp, M, 2000) put the total economic cost of autism at £1 billion a year, using the 'textbook' rate of 5 in 10,000 children. Using the Cambridge figures the true cost could be £5 billion a year.

4.37 Jarbrink and Knapp make the following estimates:

- £3 million over a lifetime for a severely-affected autistic child with learning difficulties;
- £800,000 for a person with high-functioning autism;
- £500,000 for a person with Asperger syndrome.

Suggested Prevalence Rates of Autistic Spectrum Disorders in Northern Ireland (Researched by PAPA, 9 July 2001)

4.38 The National Autistic Society published prevalence estimates for ASD in 1997. In July 2001, PAPA published estimates for Northern Ireland, extrapolating the NAS figures. The Task Group has further extrapolated these figures to estimate the prevalence of ASD in years 1 to 12 of the school system in Northern Ireland.

Table 4.1

Estimated prevalence of ASD in Northern Ireland, based on extrapolation of estimates provided by the National Autistic Society and PAPA

People with Learning Difficulties (IQ under 70)

	Approximate Rates per 10,000	Approximate Prevalence in Northern Ireland	Approximate Prevalence in School Years 1-12
Kanner Syndrome	5	845	153
Other Spectrum Disorders	15	2,536	457
Total	**20**	**3,382**	**610**

People with Average or High Ability (IQ 70 or above)

	Approximate Rates per 10,000	Approximate Prevalence in Northern Ireland	Approximate Prevalence in School Years 1-12
Kanner Syndrome	36	6,087	1,098
Other Spectrum Disorders	35	5,918	1,068
Total	**71**	**12,006**	**2,166**

Possible Total Prevalence of all Autistic Spectrum Disorders

Approximate Rate per 10,000	**Approximate Prevalence in NI**	**Approximate Prevalence in School Age Children**
91	15,388	2,776

Sources of Information

Websites accessed on 9 July 2001

4.39 Northern Ireland Statistics and Research Agency

- ❖ Estimated population in Northern Ireland on 30 June 1999 was 1,691,000.
- ❖ Population in the school system years 1 to 12, in June 2000, was 305,162.

4.40 National Autistic Society (June 1997)

- ❖ Fact Sheet: 'How many people have autistic spectrum disorders?'
- ❖ Prevalence rates can vary widely, and are affected by a variety of factors as outlined above.

A Survey of Autism Prevalence Rates in Northern Ireland - 2000/2001

4.41 This section examines the difficulties in attempting to establish autism incidence and prevalence figures for Northern Ireland. Prevalence refers to the number of children with ASD within a defined population, eg the number of children with ASD in mainstream primary schools or the number with ASD in year 3 across all schools. Incidence refers to the rate of detection of ASD, ie the number of ASD children detected within a defined period of time within a particular population, eg the number diagnosed in the Down Lisburn Trust during the year 2000.

4.42 Listed below are a number of difficulties encountered when attempting to estimate the prevalence of ASD in pre-school and school-age children.

Lack of Effective Data-gathering Methods

4.43 Only 2 of the ELBs surveyed had created effective and reliable databases to record information relating to children diagnosed as having ASD. Information from the remaining 3 ELBs had to be obtained from outreach support staff working in the area of autism or by asking educational psychologists to collate information from children's files.

Differential Practice in Relation to Assessment and Diagnostic Procedures

4.44 There are differences in diagnostic procedures across and within ELBs. Debate continues as to the most effective diagnostic methods, and the key professionals who should be involved in the assessment and diagnostic process. As outlined in some detail in Chapter 5, practice remains diverse.

4.45 The situation is complicated by the fact that there is no obvious or defining biological marker or medical test that can be used as a basis for diagnosis.

4.47 There is no agreement on appropriate diagnostic systems to be used.

4.48 There is confusion arising from the use of varied and imprecise terms such as autism, autistic spectrum disorders, autistic tendencies, Asperger syndrome, and higher-functioning autism.

4.49 There is overlap with other disorders such as Specific Language Impairment and Attention Deficit with Hyperactivity Disorder (ADHD).

Lack of Agreement and Debate in Relation to Appropriate Diagnostic Criteria

4.50 The debate continues as to the criteria that should be used for the purposes of diagnosis:

- Kanner's criteria;
- DSM-III-R (The American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders);
- DSM-IV (the 4th edition of the above, 1994);
- ICD-10 (The World Health Organisation's International Classification of Diseases);
- Wing and Gould - the 'triad' of impairments;
- more inclusive criteria to take account of social difficulties as suggested by Sula Wolff.

4.51 There does not appear at present to be a co-ordinated and standardised approach to the assessment and diagnostic process.

Diversity in the Use of Standardised Tests to be Used as an Aid to Diagnosis

4.52 Choice of assessment materials and techniques is largely governed by the personal preferences of the professionals concerned. It is therefore of no surprise that there is considerable diversity in assessment practices and in assessment outcomes.

Lack of Agreement in Relation to Terms Used to Describe the Condition

4.53 Terms used to describe children with Autistic Spectrum Disorders vary widely according to the interest levels, knowledge base, skills and experience of the various professionals involved. Across and within ELBs, professionals use a range of terms that make it very to difficult to be specific, or to differentiate between categories such as ‘higher functioning autism’ and ‘Asperger syndrome’. Descriptive terms used in Northern Ireland include the following:

- autism;
- autistic spectrum disorder;
- autistic tendencies;
- on the autistic spectrum;
- autistic spectrum difficulties;
- displays traits consistent with an ASD/autism, Asperger syndrome or Pervasive Developmental Disorder;
- Pervasive Developmental Disorder not otherwise specified.

Difficulty in Differentiating between Autism and Asperger Syndrome

4.54 Within Northern Ireland, unless professionals have been participating in an organised assessment and diagnostic procedure, and have reached some agreement on the definition of terms to be used, it is very difficult to extract, for example, children with Asperger syndrome, from those with the general description of ASD. This factor has resulted in there being insufficient data relating to children with Asperger syndrome across most of the ELBs. The survey therefore does not attempt to quantify the prevalence of Asperger syndrome.

4.55 During the collection of data, however, it has been noted from perusal of psychologists’ and teachers’ comments, that there is an increasing prevalence of Asperger syndrome within mainstream settings. The following data from the Southern Education and Library Board (SELB) indicate that, while most children are diagnosed as having autism, the proportion diagnosed as having Asperger syndrome is increasing.

Table 4.2

Increase in prevalence of ASD and of Asperger syndrome over a 3-year period 1999-2001 in SELB

	1999	**2000**	**2001**	**% increase**
Autistic	100	138	181	81%
Asperger	26	34	67	158%
Total ASD	**126**	**172**	**248***	**97%**

4.56 In the 3 years since SELB established a database, the recorded numbers of children with ASD has almost doubled. The rate of increase in diagnosis is greatest for children with Asperger syndrome. While the total number of children with ASD rose by 97% between 1999 and 2001, the number with autism rose by 81% and the number with Asperger syndrome rose by 158%. The NAS/PAPA data presented previously in Figure 4.1 suggest that the true prevalence rate for Asperger syndrome is higher than that for autism. This is not yet the case in SELB, so one may anticipate a continuing acceleration in the detection of Asperger syndrome.

Collection of Data - Rationale

4.57 Because of difficulties relating to the following areas:

- differential practice in relation to assessment and diagnosis, according to ELB;
- difficulty in gathering accurate and up-to-date information relating to numbers of children with ASD and Asperger syndrome;
- non-standardisation of diagnostic criteria used;

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* There is a small disparity between this figure and that of 242 quoted in the next section. This arises from data being collected at two different times.

- lack of standardised practice in use of terms and in order to examine the implications for educational provision for children with ASD,

it was decided to group the data under 3 main headings:

- ASD pupils attending SLD schools;
- ASD pupils attending MLD schools, MLD units, and any other special schools or units (eg Speech and Language units);
- ASD pupils attending mainstream schools or nursery schools/pre-school playgroups.

4.58 While the survey, therefore, cannot clarify the differential prevalence of different types of autistic spectrum disorder, it may be able to throw light on current and future levels of demand for provision in these 3 sectors of the school system.

4.59 In very approximate terms, it may be assumed that pupils in SLD schools are more likely to have needs similar to those carrying a diagnosis of Kanner's syndrome/classic autism, while those attending mainstream schools are more likely to have needs approximating more closely to a diagnosis of Asperger syndrome or high functioning autism. It should be remembered, however, that each child with ASD is an individual with his/her own particular pattern of strengths and weaknesses.

4.60 In the following sections prevalence levels are outlined and discussed on a board-by-board basis, and the levels for the whole of Northern Ireland are considered in a concluding section. The Task Group then makes recommendations relating to future practice.

NB In the tables and figures below, years 1-12 are the twelve years of compulsory schooling. Children enter year 1 if they have reached the age of 4 by the preceding 1 July. Year 0 is the immediate pre-school year, and year -1 is the preceding year: children aged 2/3 years.

South Eastern Education and Library Board (SEELB)

4.61 See Figure 4.1

Graphs showing the total numbers of children with ASD in SEELB and the numbers of children with ASD in SLD, MLD and other special schools and units, and in mainstream education.

Table 4.3

ASD prevalence in SEELB

	Number of Children	**% of Total ASD Population**
Mainstream	108	39
MLD and Other Units	62	22
SLD	106	38
Total ASD Numbers	**276**	
Total ASD Numbers Years 1-12	**233**	

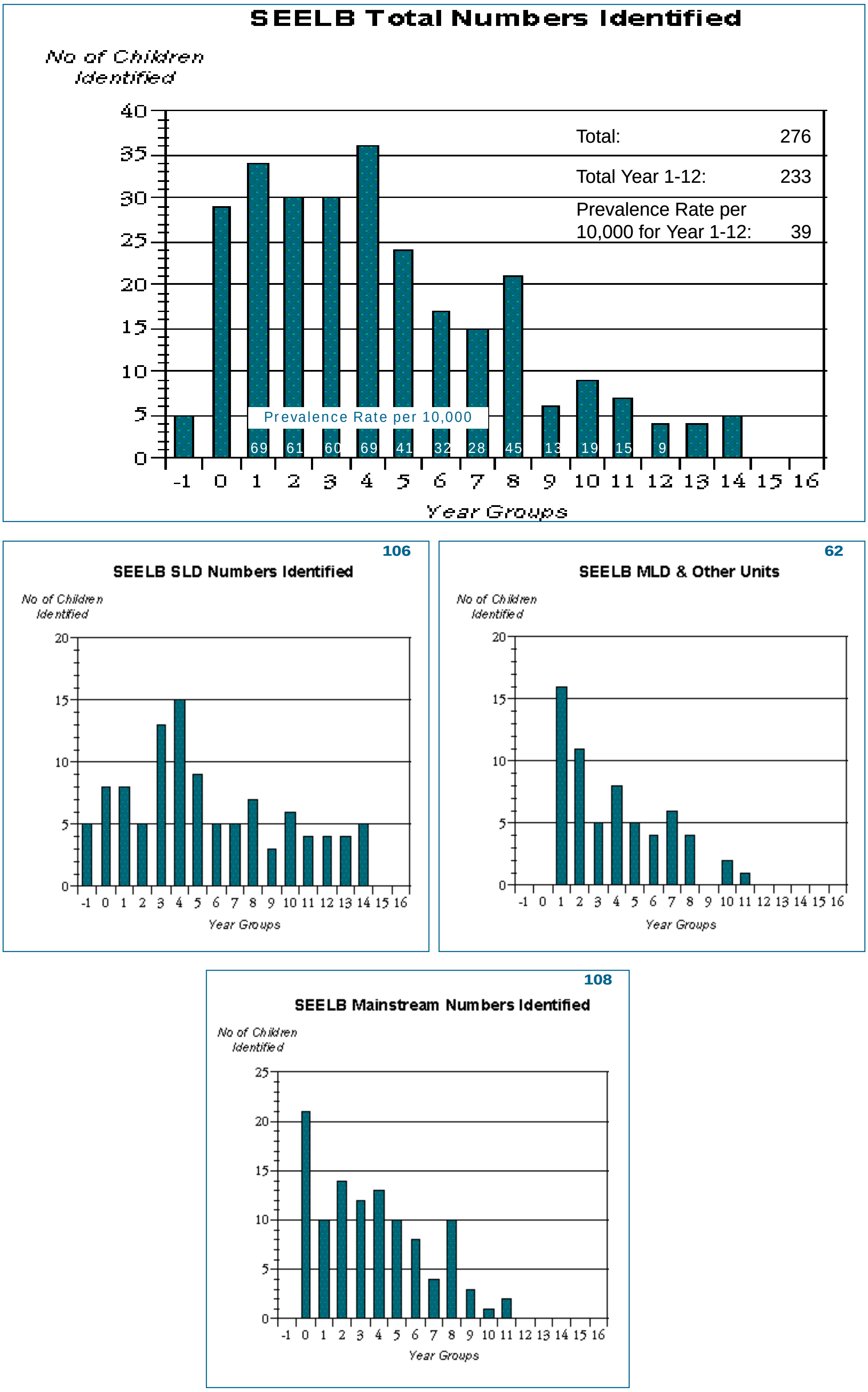
School Population = 59,460 (Years 1 to 12)
ASD numbers = 0.39% of school population (39 per 10,000)

Comment

4.62 The above statistics were collated by outreach support teachers of ASD from their manual files and relate to children who have been referred to SEELB's support service for children with ASD, and separately from the records of SLD schools.

4.63 Figure 4.1 shows that prevalence rates are considerably higher in the early years of nursery and primary education, than in late primary and secondary. This pattern applies in mainstream schools, special schools and units. This indicates either that there are more children with ASD in the primary sector than in post-primary, or that there are many pupils with ASD in the post-primary sector who have not received a diagnosis.

Figure 4.1


SEELB Total Numbers Identified
No of Children Identified
40
35
30
25
20
15
10
5
0
Total: 276
Total Year 1-12: 233
Prevalence Rate per 10,000 for Year 1-12: 39
Prevalence Rate per 10,000
69
61
60
69
41
32
28
45
13
19
15
9
-1 0 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16
Year Groups
106
SEELB SLD Numbers Identified
No of Children Identified
20
15
10
5
0
-1 0 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16
Year Groups
62
SEELB MLD & Other Units
No of Children Identified
20
15
10
5
0
-1 0 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16
Year Groups
108
SEELB Mainstream Numbers Identified
No of Children Identified
25
20
15
10
5
0
-1 0 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16
Year Groups

4.64 The overall prevalence rate (39 per 10,000) in SEELB is higher than in other board areas. The Task Group believes that this high rate is a reflection of the level of diagnostic activity in the area over a number of years. Although relatively high for Northern Ireland the prevalence rate is still much lower than the underlying rate suggested by NAS (91 per 10,000, see Table 4.1)

4.65 It is notable that the prevalence rate in SEELB appears to be similarly high (roughly 60 to 70 per 10,000) for children in years 0 through to 4. This suggests that a large majority of children with ASD have already been identified by the time they have completed their nursery year, and that a high rate of early detection has been occurring in this board area for several years. If this rate of detection is sustained, the current number of 233 children in years 1-12 can be expected to grow to roughly 420 over the next 8 years (a 180% increase).

4.66 Examination of Figures 4.2 to 4.4 suggests that early detection is currently less likely to occur in other board areas.

4.67 In the SEELB area, terms used to describe the condition include the following:

- pervasive developmental disorder;
- autistic spectrum disorder;
- autistic spectrum difficulties;
- autism;
- on the autistic spectrum;
- displays traits consistent with an ASD/autism;
- Asperger’s syndrome.

4.68 Assessment and diagnostic processes also differ across Health and Social Services Trusts within SEELB. The ELB noted, while providing data for this survey, that rate of referral also varied from Trust to Trust within the board.

Southern Education and Library Board (SELB)

4.69 See Figure 4.2

Graphs showing the total numbers of children with ASD in SELB, numbers of children with ASD in SLD Provision, MLD and other units, and in mainstream education.

Table 4.4

ASD prevalence in SELB

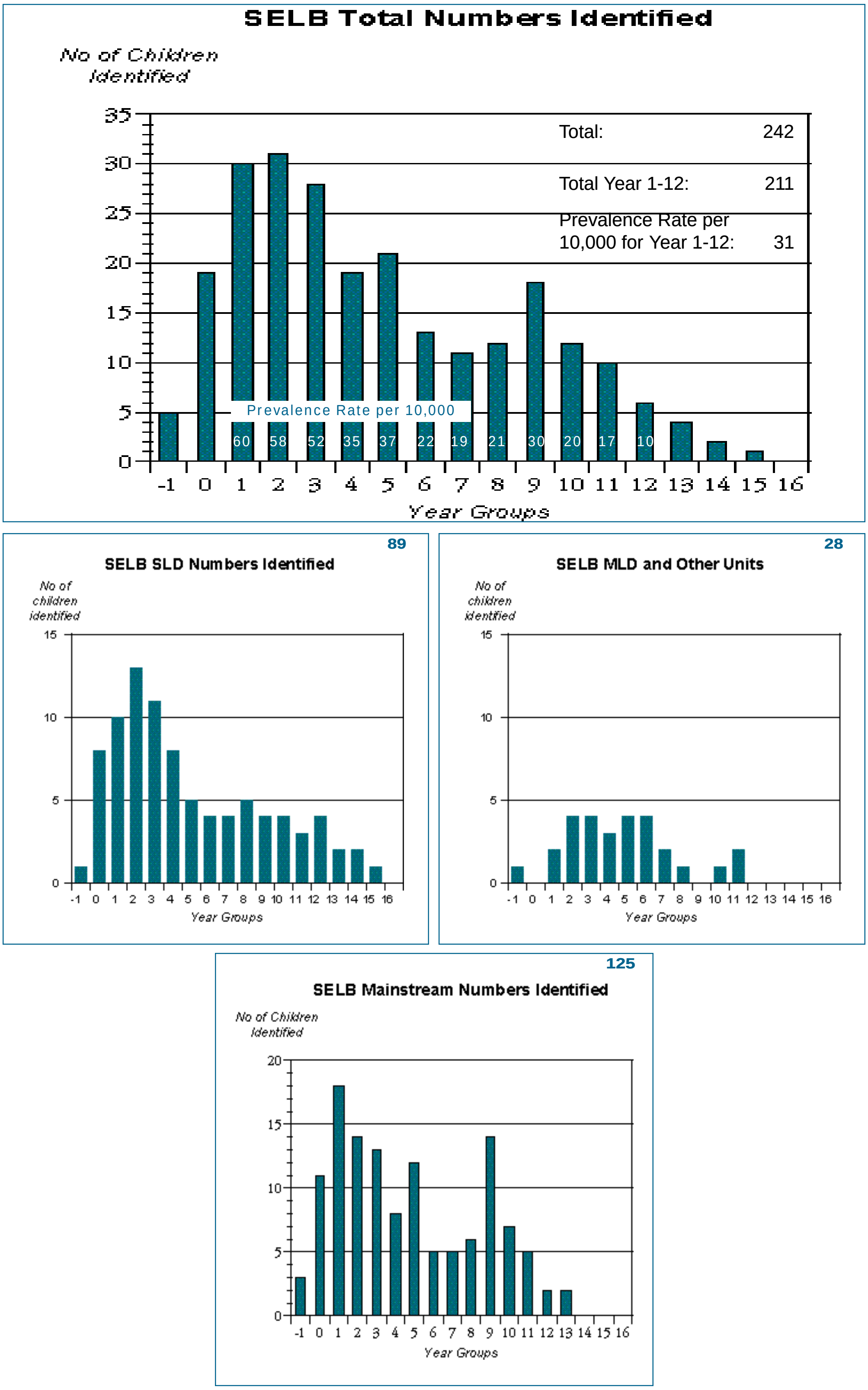
	Number of Children	% of Total ASD Population
Mainstream	125	52
MLD and Other Units	28	12
SLD	89	37
Total ASD Numbers	**242**	
Total ASD Numbers Years 1-12	**211**	
Total Asperger’s syndrome	**67**	**28**
Total Girls	**40**	**17**

School Population = 67,725 (Years 1 to 12)
ASD numbers = 0.31% of school population (31 per 10,000)

Comment

4.70 SELB has maintained a database over the 3 years 1999-2001. Multi-disciplinary, multi-agency diagnostic and assessment teams are currently being established in the area. Diagnosis is the responsibility of the paediatrician, who then forwards the diagnosis to the Principal Educational Psychologist who is the line manager for the Advisory Officer for Autistic Spectrum Disorder. Information pertaining to ASD children is then stored on the ELB’s database, and thus should be identical to the numbers recorded by the relevant Trusts.

Figure 4.2


SELB Total Numbers Identified
No of Children Identified
35
30
25
20
15
10
5
0
Total: 242
Total Year 1-12: 211
Prevalence Rate per 10,000 for Year 1-12: 31
Prevalence Rate per 10,000
60
58
52
35
37
22
19
21
30
20
17
10
-1 0 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16
Year Groups
89
SELB SLD Numbers Identified
No of children identified
15
10
5
0
-1 0 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16
Year Groups
28
SELB MLD and Other Units
No of children identified
15
10
5
0
-1 0 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16
Year Groups
125
SELB Mainstream Numbers Identified
No of Children Identified
20
15
10
5
0
-1 0 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16
Year Groups

4.71 Overall the prevalence of ASD in SELB is a little lower than in SEELB and similar to that in BELB. It is lower than the underlying prevalence rate suggested by NAS/PAPA (Table 4.1). It has grown by 97% over the last 3 years (Table 4.2) and may be expected to continue to rise. At present there are 211 pupils with ASD in years 1 to 12. If the prevalence rate rises to 70 per 10,000 (as is suggested in the concluding section) the number of pupils with ASD will grow to about 470 (a 220% increase) over the next decade.

4.72 The SELB prevalence figures (Figure 4.2) for the early years suggest that while most children with ASD have been detected by the end of year 1, there are still many who remain undetected during their nursery year. Prevalence is highest in years 1 to 3 in both mainstream and SLD sectors; the pattern is less clear in MLD and other units perhaps because the numbers are low. SELB has no MLD schools. This higher prevalence in the early years appears to correlate with the emergence of more effective diagnostic procedures, transparent referral routes, and planned and organised support services in the area over the last few years.

4.73 The majority of children diagnosed as having ASD are placed in SLD and mainstream environments. SELB employs a full-time Advisory Officer and peripatetic support staff, whose remit is to offer advice and support to children, families and teaching staff. Such support leads to raised awareness on the part of EPs and teaching staff, and may contribute to higher identified numbers of ASD children within mainstream schools.

4.74 As noted in Table 4.2, the rate of diagnosis of Asperger syndrome is increasing rapidly in the SELB. As children with Asperger syndrome are often placed in mainstream settings, this circumstance may in part explain the high proportion of ASD pupils in the mainstream sector (52%).

Western Education and Library Board (WELB)

4.75 See Figure 4.3

Graphs showing the total numbers of children with ASD in WELB, and the numbers of children with ASD in SLD provision, MLD and other special schools and units, and in mainstream education.

Table 4.5

ASD prevalence in WELB

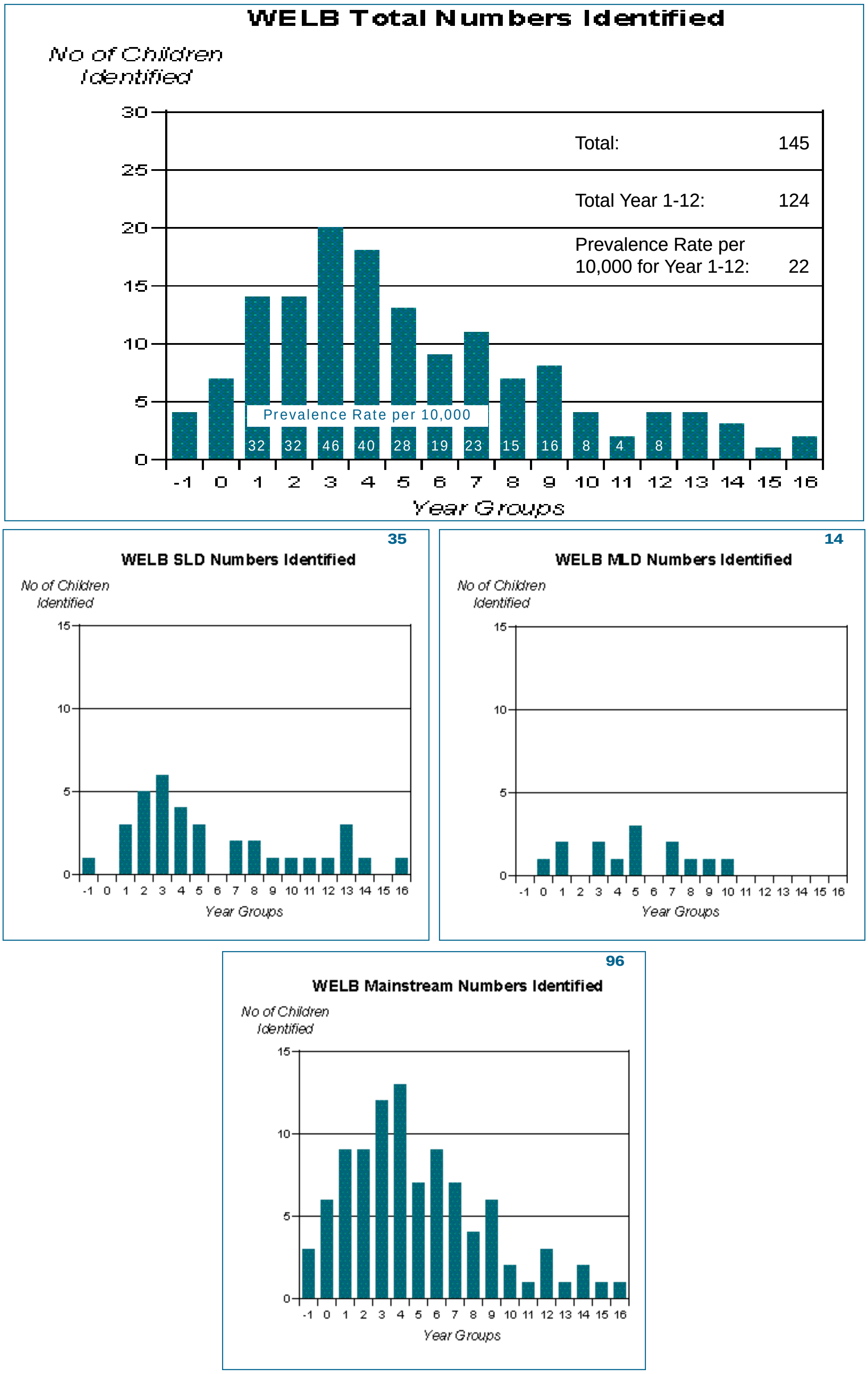
	Number of Children	% of Total ASD Population
Mainstream	96	66
MLD and Other Units	14	10
SLD	35	24
Total ASD Numbers	**145**	
Total ASD Numbers Years 1-12	**124**	

School Population = 56,274 (Years 1 to 12)
ASD numbers = 0.22% of school population (22 per 10,000)

Comment

4.76 In WELB the known prevalence (22 per 10,000) of ASD is considerably lower than in at least 3 other ELBs and very much below the underlying prevalence rate suggested by NAS/PAPA (Table 4.1). The Task Group suggest that the data should be taken as evidence of significant under-diagnosis in WELB area. Currently WELB is aware of 124 children with ASD in years 1 to 12. If, as argued in the concluding section, the prevalence rate may rise to 70 per 10,000, then the number of children with ASD will rise to about 390 (a 318% rise) over the next decade.

Figure 4.3


WELB Total Numbers Identified
No of Children Identified
30
25
20
15
10
5
0
Total: 145
Total Year 1-12: 124
Prevalence Rate per 10,000 for Year 1-12: 22
Prevalence Rate per 10,000
32
32
46
40
28
19
23
15
16
8
4
8
-1 0 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16
Year Groups
35
WELB SLD Numbers Identified
No of Children Identified
15
10
5
0
-1 0 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16
Year Groups
14
WELB MLD Numbers Identified
No of Children Identified
15
10
5
0
-1 0 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16
Year Groups
96
WELB Mainstream Numbers Identified
No of Children Identified
15
10
5
0
-1 0 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16
Year Groups

4.77 Figure 4.3 shows that the highest prevalence is in years 3 and 4 and this pattern is most marked in the mainstream sector. Prevalence is higher in the northern part of the board than in other parts, and this may reflect the existence of multi-agency diagnostic arrangements in the Foyle Trust and the absence of such arrangements in the Sperrin Lakeland Trust.

4.78 The very high proportion (66%) of children with ASD attending mainstream schools is worthy of note and the reasons for this should be investigated.

North Eastern Education and Library Board (NEELB)

4.79 See Figure 4.4

Graphs showing the total numbers of children with ASD in NEELB, and the numbers of children with ASD in SLD provision, MLD schools and other schools and units, and in mainstream education.

Table 4.6

ASD Prevalence in NEELB

	Number of Children	% of Total ASD Population
Mainstream	22	20
MLD and Other Units	38	34
SLD	52	46
Total ASD Numbers	**112**	
Total ASD Numbers Years 1-12	**99**	

School Population = 66,783 (Years 1 to 12)
ASD numbers = 0.15% of school population (15 per 10,000)

Comment

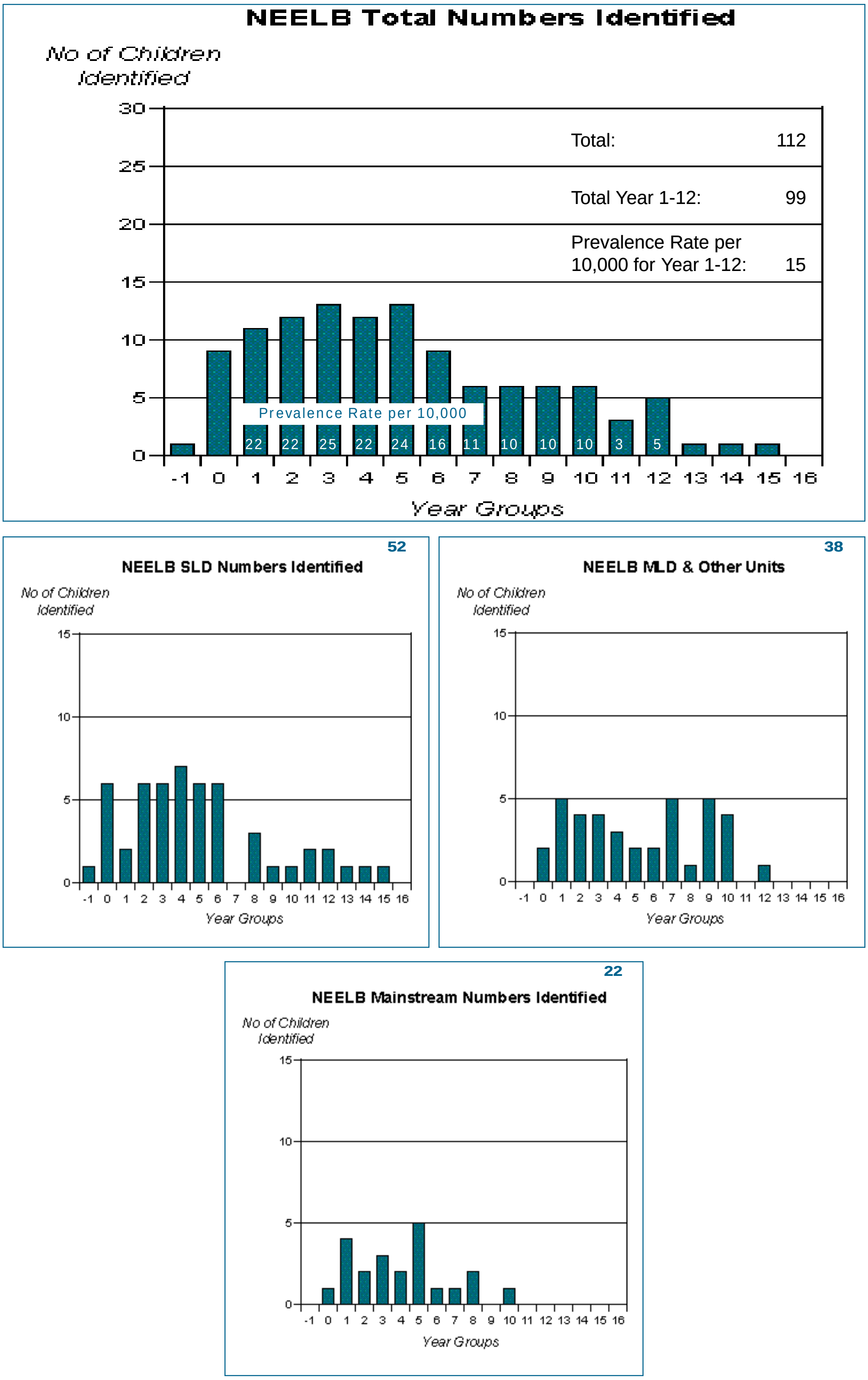
4.80 The known prevalence of ASD (15 per 10,000) is lower than in all other boards, and is between one-third and one-half of the prevalence in the 3 highest ELBs. The patterns of prevalence notable in the other boards are much less evident in NEELB (Figure 4.4) and the Task Group suggest that this is a consequence of the overall detection rate being very low ie there is a relative lack of systematic diagnostic activity and data gathering. Plans for establishment of 3 multi-agency, multi-disciplinary clinics are at an advanced stage (Chapter 5). Once these have been in operation for some time the Task Group anticipate that prevalence figures will rise and the highest figures will initially be seen, as in other ELBs, in the lower primary years of schooling. The North Eastern Board are aware of 99 children at present in years 1 to 12. The Task Group anticipates that this figure will rise to approximately 470 over the next decade. This is based on the assumption that the prevalence rate will rise to around 70 per 10,000 as argued in the concluding section of this chapter.

4.81 The Task Group considers the total number of children identified in NEELB as having an ASD to be a significant under-estimation of the true prevalence of ASD.

4.82 The range of descriptive terms used in NEELB is as follows:

- On the autistic spectrum - not diagnosed;
- Diagnosed autism;
- Autistic Spectrum Disorder - not diagnosed;
- Asperger syndrome.

Figure 4.4


NEELB Total Numbers Identified
No of Children Identified
30
25
20
15
10
5
0
Total: 112
Total Year 1-12: 99
Prevalence Rate per 10,000 for Year 1-12: 15
Prevalence Rate per 10,000
22
22
25
22
24
16
11
10
10
10
3
5
-1 0 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16
Year Groups
52
NEELB SLD Numbers Identified
No of Children Identified
15
10
5
0
-1 0 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16
Year Groups
38
NEELB MLD & Other Units
No of Children Identified
15
10
5
0
-1 0 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16
Year Groups
22
NEELB Mainstream Numbers Identified
No of Children Identified
15
10
5
0
-1 0 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16
Year Groups

Belfast Education and Library Board (BELB)

4.83 See Figure 4.5

Graphs showing the total numbers of children with ASD in BELB, and numbers of children with ASD in SLD Provision, MLD and other special schools and units, and in mainstream education.

Table 4.7

ASD prevalence in BELB

	Number of Children	% of Total ASD Population
Mainstream	72	37
MLD and Other Units	50	26
SLD	70	36
Total ASD Numbers	**194**	
Total ASD Numbers Years 1-12	**163**	

School Population = 54,920 (Years 1 to 12)
ASD numbers = 0.30% of school population (30 per 10,000)

Comment

4.84 BELB has been building up a database for a period of 3 years. During that time, prevalence of ASD has risen. The children are counted under 3 category headings:

- a firm diagnosis of autism;
- a firm diagnosis of Asperger syndrome;
- described as being on the autistic spectrum, indicating that no firm diagnosis has been recorded, but that the child displays the triad of impairments normally associated with Autistic Spectrum Disorders or pervasive disorders. This group would also include children whose parents have refused a diagnosis.

Figure 4.5

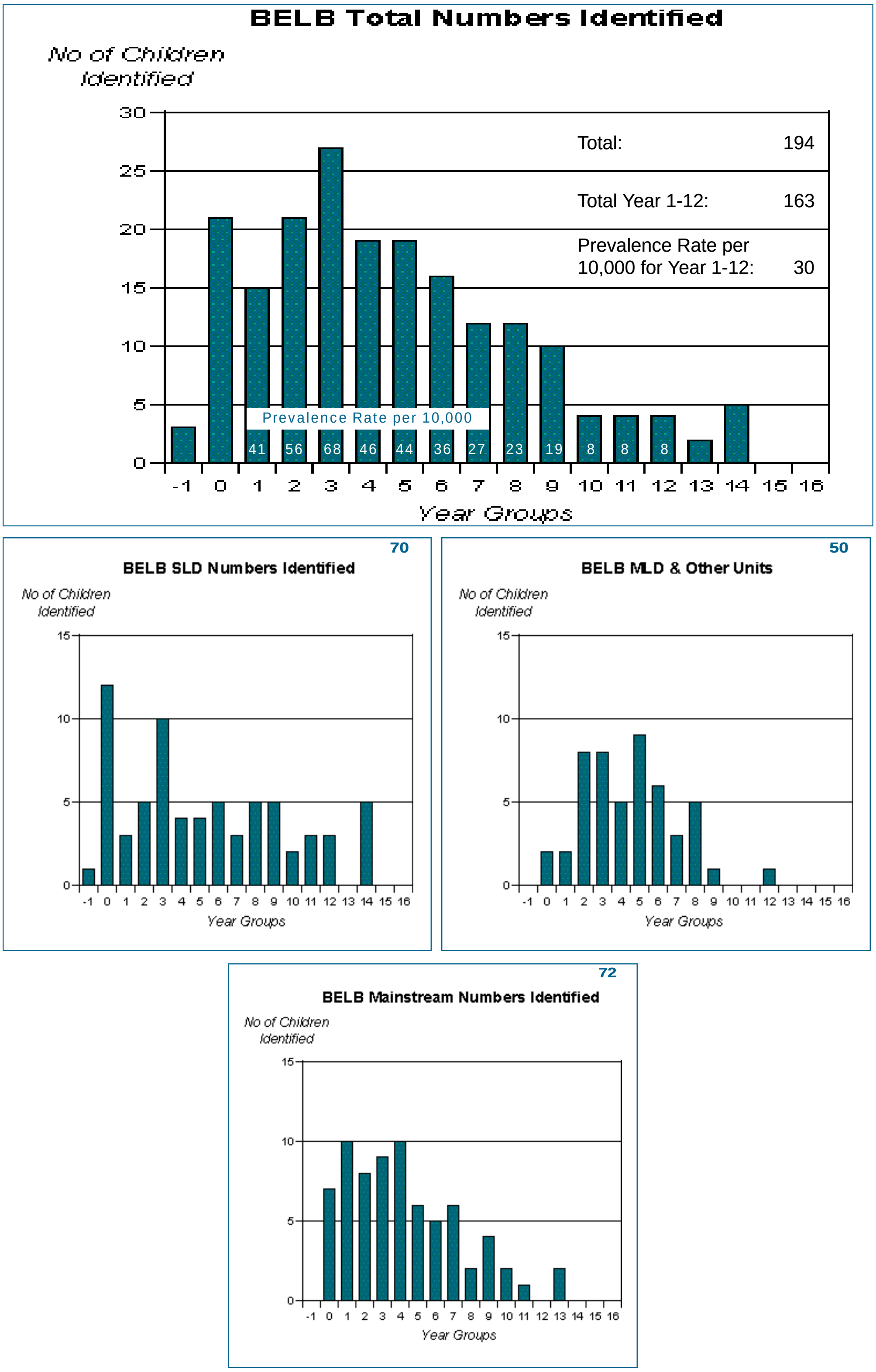

BELB Total Numbers Identified
No of Children Identified
30
25
20
15
10
5
0
Total: 194
Total Year 1-12: 163
Prevalence Rate per 10,000 for Year 1-12: 30
Prevalence Rate per 10,000
41
56
68
46
44
36
27
23
19
8
8
8
-1 0 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16
Year Groups
70
BELB SLD Numbers Identified
No of Children Identified
15
10
5
0
-1 0 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16
Year Groups
50
BELB MLD & Other Units
No of Children Identified
15
10
5
0
-1 0 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16
Year Groups
72
BELB Mainstream Numbers Identified
No of Children Identified
15
10
5
0
-1 0 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16
Year Groups

Table 4.8

BELB total numbers of ASD children recorded over a 3-year period 1999-2001

Year	Total Numbers of Children with ASD recorded
1999	89
2000	140
2001	194

4.85 This table indicates a 118% increase in recorded prevalence of ASD in the BELB area between 1999 and 2001. This increase correlates with the establishment of multi-disciplinary, multi-agency diagnostic clinics in the North and West Trust and in the South and East Trust.

4.86 The overall prevalence rate in BELB is 30 per 10,000 which is lower than in SEELB, similar to SELB and higher than in the other 2 ELB areas. It is much lower than the underlying prevalence rate suggested by NAS/PAPA ie 91 per 10,000. The BELB are aware of 163 children with ASD in years 1 to 12. If the prevalence rate rises to roughly 70 per 10,000 the number of children with ASD in years 1 to 12 will rise to about 380, an increase of about 235%, over the next decade.

4.87 The prevalence figures for the very early years in Figure 4.5 suggest that in the peak year, ie year 3, the great majority of children with ASD have already been diagnosed, but that there may be significant numbers of children in years 1 and 2 who have not yet had a diagnosis. There is a high prevalence in year 0 (nursery year), however, which may be attributable to increased early diagnostic activity arising from the 2 very recently established clinics mentioned above.

4.88 The proportion of children with ASD attending mainstream provision is 37%, a little below the average for Northern Ireland (44%). This may reflect the availability of special schools in Belfast, including a school for children with medical/health problems.

Northern Ireland Total Numbers Identified

4.89 Figure 4.6 (page 90) includes 5 graphs illustrating the total numbers of children in Northern Ireland, in each year of education, with ASD, and the numbers of children with ASD in SLD schools, MLD and other special school and units, and in mainstream education.

4.90 The number of children with ASD known to the ELBs in Northern Ireland is 967. In years 1 to 12 of the school system there are 830 children with ASD. The highest numbers are in the nursery year (year 0) and across years 1 to 4; there are, however, substantial numbers of children with ASD in years 6 to 9.

4.91 Table 4.9 indicates a prevalence rate for Northern Ireland of 27 per 10,000. This contrasts with evidence from recent reports quoted earlier in this chapter, where prevalence rates for the full autistic spectrum were as high as 58 per 10,000 (Autism Research Centre, Cambridge) or 91 per 10,000 (National Autistic Society).

4.92 The Task Group concludes that the current prevalence rate of 27 per 10,000 in Northern Ireland is low. However, closer analysis shows that the rate is much higher in some ELB areas than others, and much higher for younger children than for older children.

4.93 The first graph in Figure 4.6 illustrates clearly that there is a wave of ASD moving up through the school system. The crest of this “autistic spectrum wave” reached year 3 in the 2000–2001 academic year. It can be anticipated that as the autistic spectrum wave proceeds up through the system the numbers of children with ASD in each year group will level out. The number of children in each year will be similar, and will be high. The highest rates (see years 1 to 4 in SEELB, Figure 4.1) suggest that over the next few years the rate in Northern Ireland schools could level out at around 70 per 10,000. This estimate is based on the assumptions that the current rate of diagnosis does not increase in those areas where it is already relatively high (eg SEELB) and that the rate of diagnosis in low rate areas (NEELB and WELB) will increase to a level similar to that in the other areas.

Table 4.9

Prevalence in June 2001 of children known by Education and Library Boards to have an ASD

Area	Total ASD[1] in year 2001	Rate[2] per 10,000 for years 1-12	SLD[3]	MLD and all units[4]	Mainstream
SEELB	276	39	106 (38%)	62 (22%)	108 (39%)
SELB	242	31	89 (37%)	28 (12%)	125 (52%)
BELB	194	30	70 (36%)	50 (26%)	72 (37%)
WELB	145	22	35 (24%)	14 (10%)	96 (66%)
NEELB	112	15	52 (46%)	38 (34%)	22 (20%)
All Boards	**967**	**27**	**352 (36%)**	**192 (20%)**	**423 (44%)**

Total school population in years 1 to 12 in Northern Ireland is 305,162

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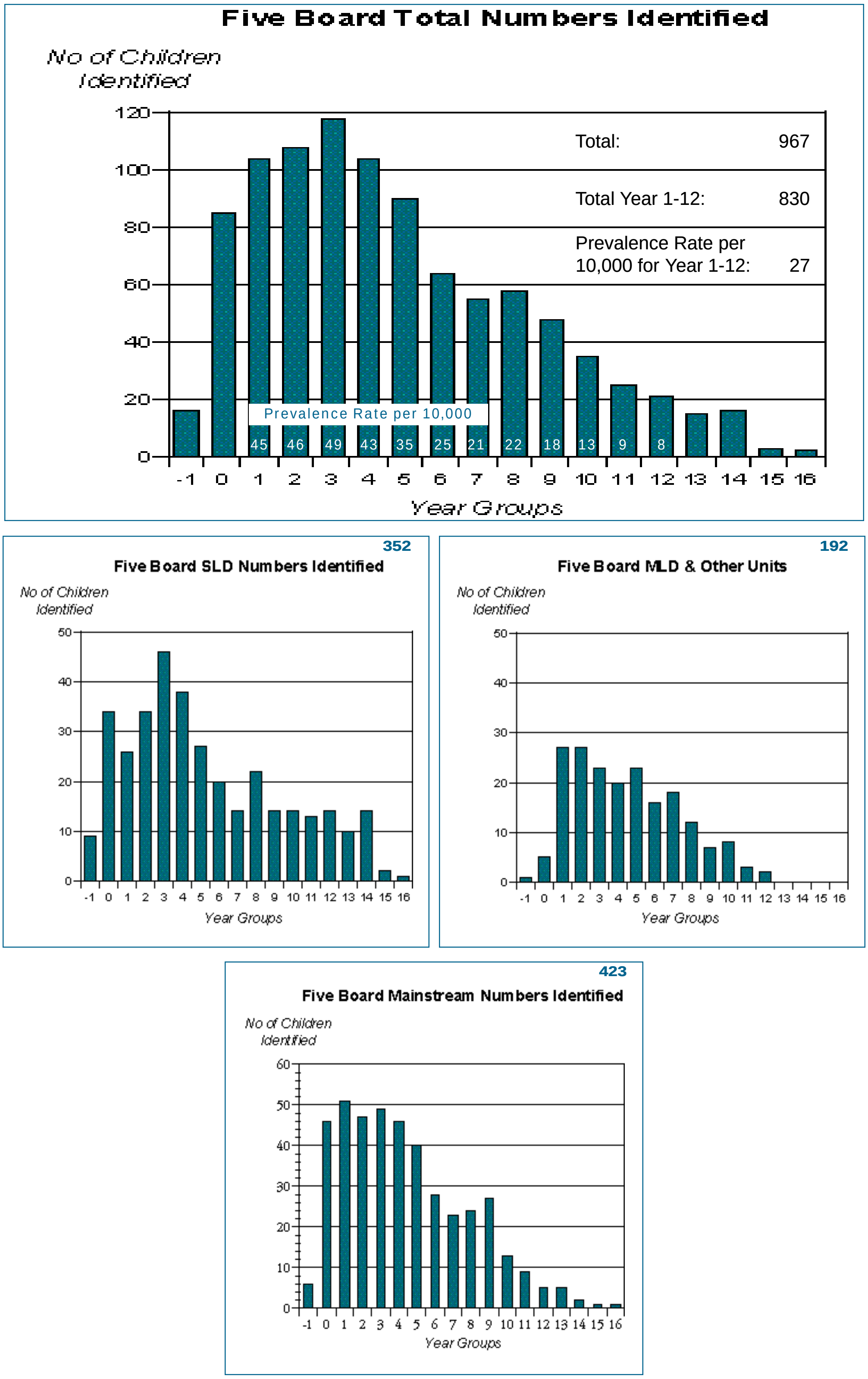
[1] These figures include all children from those who are 2 years below compulsory school age (Year 1) to those who are 4 years above compulsory school age (year 16).

[2] The rate per 10,000 is calculated only for those pupils in years 1 to 12, because it is only for these years that total school population is known.

[3] The figure in brackets is the percentage of the total ASD figure that attend SLD schools - other figures in brackets should be interpreted similarly.

[4] In this grouping are pupils with ASD who attend MLD schools or units and pupils attending any other kind of special school or unit apart from SLD schools.

Figure 4.6


Five Board Total Numbers Identified
No of Children Identified
120
100
80
60
40
20
0
Total: 967
Total Year 1-12: 830
Prevalence Rate per 10,000 for Year 1-12: 27
Prevalence Rate per 10,000
45
46
49
43
35
25
21
22
18
13
9
8
-1 0 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16
Year Groups
352
Five Board SLD Numbers Identified
No of Children Identified
50
40
30
20
10
0
-1 0 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16
Year Groups
192
Five Board MLD & Other Units
No of Children Identified
50
40
30
20
10
0
-1 0 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16
Year Groups
423
Five Board Mainstream Numbers Identified
No of Children Identified
60
50
40
30
20
10
0
-1 0 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16
Year Groups

4.94 Even if one assumes that the support services are at an adequate level at present then one could estimate that there will be a 250% increase in demand for support services in Northern Ireland schools over the next few years. Areas where the identification rate is low at present, may expect the greatest increase in demand for post-diagnosis support services. Much of the increase in demand will be in the post-primary sector. This is, however, a very conservative estimate, because the current level of post-diagnosis support services is already considered to be too low (see Chapter 5). These services are currently aware of 830 children in years 1 to 12. There will be more than 2100 in roughly 8 years' time if the current peak incidence rates become the norm across the compulsory school age range. The Further and Higher Education, training and employment sectors may expect to notice the first significant increases in numbers of young people with a diagnosis of ASD in about 4 to 5 years' time.

4.95 The Task Group notes the large variation in prevalence across ELBs. The prevalence in SEELB, SELB and BELB is 2 to 3 times greater than that recorded in WELB and NEELB. The Task Group notes that the rank ordering of these prevalence rates corresponds closely to the dates of establishment of comprehensive and broad-reaching diagnostic services in each area. It appears likely, for example, that the higher prevalence rate in the SEELB area is a result of the relatively early establishment in the Down Lisburn Trust of a very active diagnostic clinic. Given the variability in diagnostic criteria and practices, and degree of subjectivity involved in diagnosis, it remains a possibility that the relatively high rates of diagnosis in Down Lisburn Trust may not be matched in other areas even as more diagnostic clinics are established there. However, the Task Group considers that future planning should be based on the assumption that diagnosis rates in all areas will eventually match those in Down Lisburn Trust.

4.96 The data illustrated in Figure 4.6 may be interpreted as evidence of a real increase in the occurrence of ASD. The data may equally be interpreted simply as evidence of an increase in the detection and diagnosis of ASD among young children and this does not necessarily imply any real increase in the true prevalence of ASD. The data can be interpreted as evidence of both a real increase in occurrence and also an increase in detection. The variations in prevalence rates between ELBs, and the fact that they correlate with variations in the provision of diagnostic services strongly suggests that at least some of the increase in the numbers of children with ASD is due to improvements in diagnostic services.

4.97 If it is the case that at least some of the increase in numbers of children with ASD is due to improvements in diagnostic services, then it follows that in the upper-primary and post-primary years, and in Further and Higher Education, training and employment, there are many children, young people and adults with undiagnosed ASD. The primary focus of recently-developed diagnostic services is on early diagnosis (see Chapter 5). The survey data suggest that there is also a need for services to focus on the diagnosis of older individuals who have ASD but who did not, when they were younger, have access to adequate diagnostic services.

4.98 The data illustrated in Figure 4.6 show that ELBs are not aware of the ASDs of many children in year 0, and of most children in year -1 (nursery year and the year before, ie children aged roughly 3 to 4 and 2 to 3). If one assumes that there are roughly 23,000 children in each of these age groups, then the known prevalence rate in year 0 would be 37 per 10,000 and 7 per 10,000 for year 0 and year 1 respectively. If one accepts that the true prevalence rate is approximately 70 per 10,000, as argued earlier, then it follows that ELBs are aware of about only half of the ASD children aged 3 to 4 (nursery year) and are aware of about only one in 10 of children with ASD who are aged roughly 2 to 3 years.

4.99 The Task Group finds that the current systems for data collection with respect to ASD are not adequate. There is a need to develop a common system for continuous recording of incidence and that the type of information gathered should be harmonised and relevant to the needs of all ELBs and HSSTs, HSSBs and the relevant government Departments (DE, DHSSPS and DEL).

4.100 Children with ASD are being educated in a wide variety of settings. The largest proportion (44%) is in mainstream nurseries and schools. 36% of pupils with ASD are educated in SLD settings. 20% are educated in MLD schools or MLD units or other types of special schools or units. These proportions vary greatly from one ELB to another. Reasons for the variations from board to board may include differences in diagnostic arrangements, policies on inclusion, socio-geographical factors, and differences in the availability of certain types of special educational provision. The reasons for these variations appear complex and require further investigation.

CHAPTER 4

PREVALENCE AND INCIDENCE: INTERNATIONAL; NORTHERN IRELAND

RECOMMENDATIONS

Recommendation 4(i)

The maintenance by each ELB, HSST and HSSB and relevant Departments of compatible databases that can provide information necessary for planning - the Task Group recommends that the term Autistic Spectrum Disorders (ASD) be used to cover the whole range of difficulty, within which 2 subgroups - Autism and Asperger syndrome, and no other terms - should be used.

Recommendation 4(ii)

ELBs and Trusts should collaborate to consider the variation in prevalence of ASD from area to area, and to develop diagnostic services which ensure equality of access regardless of home address.

Recommendation 4(iii)

ELBs and Trusts should collaborate to consider the low detection rates for very young children and for older children, and to develop diagnostic services which ensure equality of access regardless of age.

Recommendation 4(iv)

ELBs and Trusts and providers of Further and Higher Education, training and employment should plan for significant increases in the demand for provision for individuals with ASD.

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.

CHAPTER 6

NURSERY AND PRE-SCHOOL

This chapter considers and reviews the education of children with ASD aged 3 to 4 years at pre-school and nursery settings, and makes recommendations for the development of comprehensive provision for this age group.

PREVALENCE RATES AND PROJECTIONS

6.1 The Department of Education's (DE) Pre-school Education Expansion Programme (PSEEP), which commenced in 1998/99, has helped to ensure that children under 4 years of age can access educational support at an early age and thus make early progress in preparation for formal entry to school. In respect of children with special educational needs, the DE statistical returns for the 1999/2000 year indicate that a small number of children in nursery schools and classes and in funded places in voluntary or private settings have received a Statement of Special Educational Needs. However, a significant number of children in the sector are considered by the Education and Library Boards' Educational Psychology Service as having varying degrees of special educational needs but have not yet been fully assessed. Details are as follows:

Setting	Statemented	With Special Needs
Nursery Classes	20	150
Nursery Schools	56	386
Voluntary/Private	9	47
Reception	7	51
Total	**92**	**634**

6.2 The total size of the pre-school cohort, ie the number of children in their immediate pre-school year, is estimated using P1 enrolments as a proxy figure. In October 2001, 19,919 children were in funded pre-school education. Most would have been in their immediate pre-school year, although nursery schools and classes can admit children from the age of 2 if they have places available. The number of children in funded pre-school provision is likely to be in the region of 21,500+. While it is not possible to estimate accurately the number of children at pre-school level with a diagnosis of ASD, it is evident that there are increasing numbers of children with this diagnosis under 4 years. Current figures from the boards, for children in the year before compulsory education begins, indicate that some 85 children, 46 of whom are in mainstream settings, are identified as having ASD.

6.3 The current figures show the numbers of children with a diagnosis of ASD in their penultimate year before compulsory education in each ELB:

SEELB	29
BELB	21
SELB	19
NEELB	9
WELB	7
TOTAL	**85**

6.4 Many children with ASD may not receive a diagnosis until after their pre-school years. One may estimate true prevalence in the pre-school years and the likely distribution of educational needs by reference to the figures for older children. Prevalence data presented in Chapter 4 suggests that in any one year group there may be nearly 170 children who have ASD.

6.5 The evidence cited in Chapter 4 highlights that there are a number of difficulties in relation to estimating the prevalence of ASD in Northern Ireland. This is clearly borne out by the Task Group's efforts to collate accurately the numbers of children with ASD. However, the Task Group considers that provision should be made for some 70 per

10,000 children. This clearly reveals that the present level of provision is insufficient, and will have to be reviewed and improved to meet the current and projected needs of the ASD population at the pre-school level.

RANGE OF PRE-SCHOOL PROVISION

6.6 The PSEEP is a programme to increase the number of funded places in statutory and voluntary settings to provide a place for every 4 year old in their immediate pre-school year whose parents wish to avail of it. Planning at local level is carried out by a Pre-school Education Advisory Group (PEAG) in each ELB area. The PEAGs consist of representatives from the education, health and social services and voluntary sectors. Regulations require that priority should be given to children from families on income support or job-seekers' allowance who just missed out on a year one* place due to their July-August birthdays. The next groups of pupils to be provided funded places are those with September-July birthdays and similar socially disadvantaged backgrounds, followed by children with July and August birthdays without socially disadvantaged backgrounds, and finally any child aged 3 before 1 September in their immediate pre-school year from a family who has requested a place. Thereafter, individual schools set their own criteria. While pupils with special educational needs can access pre-school provision, they do not receive priority and placement can be problematic.

Belfast Education and Library Board (BELB)

6.7 There are currently 21 year 0 children with ASD in BELB, 14 of whom are enrolled in specialist provision.

6.8 They receive services in varying ways:

- ❖ two psychologists with special interest in this area work with children in nurseries and co-work with individual psychologists in the areas of identification, assessment and intervention;

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* NB Year one is the first year of compulsory (primary) education: children who reach the age of 4 by the preceding 1 July. Year 0 means the year before year one.

- children at Stage 3 and above in the Code of Practice are filtered through a panel of psychologists and Assistant Advisory Officers and are referred to the Oakwood Support Team as appropriate. This team has one full-time teacher and 5 classroom assistants deployed as required in the mainstream nurseries and primary schools attended by these children. The Oakwood Support Team or educational psychologists endeavour to support these pupils at time of transfer into year one at primary school. However, rapidly increasing numbers make it impossible to provide this support for every child referred;

- The Oakwood Assessment Centre offers a nursery class with teachers who have experienced varying amounts of training. Teachers here, as elsewhere, have not been able to access all the training that they think they need;

- in the voluntary sector Segal House, a playgroup run by MENCAP, are in the initial stages of setting up structured teaching programmes for children with ASD;

- Forward Steps service funded by Barnardo's have specialised staff trained in ASD with experience in running effective programmes. Their pre-school TEACCH programme received a positive evaluation from Queen's University. Their current programme, putting greater emphasis on inclusion, assists with the integration of children with ASD into a mainstream setting and suggest strategies for use in the home environment.

6.9 Oakwood and Segal House have speech and language therapists, occupational therapists and physiotherapists who work on site, in close contact with parents and teaching staff. Their work is highly valued. Parents and professionals interviewed felt that the amount of therapy for children was often inadequate.

6.10 Training has been provided for teachers and classroom assistants from the Educational Psychology Service, Oakwood Support Team, the National Association for Special Educational Needs, PAPA, and the Behavioural Support Team. A coherent strategy for the co-ordination of training would be of great benefit.

Southern Education and Library Board (SELB)

6.11 There are 19 children in their final pre-school year (year 0) known to the ASD service in the SELB. Eight children are placed in special schools, and 11 in mainstream provision.

- The Board makes additional assistance available to the nursery schools or classes with children who have special educational needs and for those who have statements of special educational needs.
- From September 2001 up to 10 places will be available for children with severe and complex difficulties in each of the early years programmes which are located in 3 of the Board's special schools. It is expected that places in these nurseries will be offered to children with ASD or suspected traits. Priority is given to those in year 0. Names are put forward by the Educational Psychology Service and the Consultant Community Paediatricians for discussion at Advisory Panel Meetings which include an Assistant Advisory Officer from the Special Education section, the Principal Educational Psychologist, the Consultant Community Paediatrician and the Area Senior Educational Psychologist. An Admission Panel comprised of special education staff then meet to decide to whom places will be offered. Those who gain access to these places have access to specialist staff, speech and language therapists, occupational therapists and physiotherapists, who provide an holistic service on site.
- The Southern Board employs one full-time peripatetic teacher who supports nursery-aged pupils in mainstream schools. These pupils are referred to the ASD support service by the school Principal or at the request of Medical Officers. At the point of referral the pupils' names go on to a waiting list and

they are given support as soon as possible. The peripatetic teacher is also responsible for primary, and many post-primary, pupils throughout the Board area. The numbers on the caseload are ever-increasing as seen in Chapter 4. The children may have to wait some time before support is available to them.

❖ There is one specialist educational psychologist in the Board area. A number of psychologists have an interest in ASD and all support the pupils on an individual basis.

6.12 HSS support in mainstream provision is patchy and therapists cite lack of resources as the reason for this. Therapy on site is viewed by speech and language therapists as excellent practice. It is available on site in SLD schools and in a number of Learning Support Centres attached to schools.

Western Education and Library Board (WELB)

6.13 The number of children with ASD in year 0 in the WELB is 7, and one of these is enrolled in special provision.

6.14 Special schools in this Board area have nursery places available for pupils from the age of 3 years. Referrals to the schools usually originate from the peripatetic pre-school service or Consultant Community Paediatricians. The teachers in nursery settings in special schools may not be specialist teachers trained in accommodating the learning styles of pupils with ASD; however, many do have initial training in structured teaching principles and related methods. This reflects the difficulty in accessing an adequate number of places on training courses related to ASD.

6.15 The ASD advisory service currently consists of one teacher and one classroom assistant. They are based in Foyleview school and their work is focused primarily in the Foyle district. WELB anticipates the imminent appointment of similar staff to provide support in southern parts of the board’s area. The advisory service staff are available for training and advice in mainstream nurseries and playgroups though not for direct intervention. The Educational Psychology Service provides advice and support on an individual basis throughout the ELB.

6.16 Teaching staff in nurseries and playgroups are often not trained in ASD. They therefore feel ill-equipped to meet the needs of children with ASD. Teachers would appreciate more training and support to help these pupils integrate and benefit from their pre-school years. Additional classroom assistance is not provided unless a statement is available for the child, although emergency assistance is available in some cases.

North Eastern Education and Library Board (NEELB)

6.17 In the NEELB area there are currently 9 children with ASD in year 0, of whom 8 attend special provision.

6.18 Special schools in the NEELB area have nursery places available for pupils from 3 years old. The teachers may not have specialist training in teaching pupils with ASD due to the small number of places available on training courses. However the special school staff in the nursery sector will often have had access to initial training in ASD and are likely to have been given an overview of intervention methods, by attending training courses arranged by PAPA or in-service courses delivered by the ASD field officer.

6.19 The remit of the ASD field officer includes direct support to nursery school pupils who have a statement of special educational needs. At present there is only one child in the nursery age range eligible to access this support.

6.20 There is an obvious gap in the service as many nursery and playgroup teachers report difficulties in teaching children with ASD in non-specialist provision with no support and at times no consistent classroom assistance unless a statement has been provided. Training is an issue for teachers and classroom assistants in mainstream nurseries and playgroups. Many have gained knowledge from having children with ASD in their classrooms in previous years and from access to support from the ASD field officer. However, all teachers questioned for the purpose of this report indicated that they would benefit greatly from structured training and more access to specialist support staff.

6.21 Therapists view in-school support for ASD pupils as essential but they cite limited resources as the reason for the lack of this form of support in most schools In some schools there are examples of good practice where the therapists are trained in ASD and are providing excellent advice and support.

South Eastern Education and Library Board (SEELB)

6.22 In the South Eastern Board there are 29 Year 0 pupils with ASD and 8 of them are enrolled in special provision. Once a referral has been made to the ASD advisory service from educational psychology or a Board officer an assessment (Psycho-Educational Profile Revised, PEP R) is completed. Following this the child's parents are contacted to discuss the results of the assessment and to inform them of the advice given to school and of the training available to them, delivered by SEELB and Down Lisburn Trust.

6.23 The Keyhole Early Intervention Project for Autism, administered by PAPA, is a partnership of agencies and individuals. It is currently delivering a package of training to pre-school staff. The training is designed by staff from Down Lisburn Trust, Barnardo's and SEELB and it is delivered through the Northern Ireland Pre-school Playgroups Association (NIPPA). Training of 5 weeks' duration is available to NIPPA staff. Support is given at nursery level by the ASD advisory support team and by speech and language therapy.

6.24 Whilst these services are available, advisory support staff report that services are stretched and numbers of children with ASD are ever-increasing. This makes it difficult to provide a seamless service to staff and pupils. More staff on the ASD teams and more HSS therapists specialised and trained in ASD would enhance the service already provided.

Range of Provision: Comments from Parents

6.25 Parents report very varying experiences of early support and nursery provision. The 2 examples given below faithfully represent the actual experiences of a number of parents and have been presented in a manner designed to protect the identities of those involved.

> ***'We were shocked to receive the diagnosis but relieved. I realize that my son was fortunate to get the diagnosis at an early age. Support after diagnosis at home and in school would have been very welcome. We had no services made available to us for many months after our child was diagnosed and felt very isolated The situation has been very difficult and very badly managed by the school.'***

6.26 Rory was placed in a nursery attached to a mainstream primary school with part-time classroom assistance. The staff had received no training and were ill-equipped to manage him. He was aggressive towards other children at times and required a lot of one-to-one attention. Rory's mother dreaded going to collect him as there were constant complaints about his behaviour and lack of attention. Staff felt he was disruptive to other pupils. Eventually the situation deteriorated so much that the Principal decided Rory was too disruptive in school and they were unable to sustain his placement. His mother was told that he could no longer attend the nursery, there was no further discussion about the decision or plan devised as to how provision could be reintroduced.

6.27 Rory's mother expressed her sadness and frustration at having to see Rory, unable to understand the disruption in routine, go out into the car in the mornings and put his seat belt on ready to go to school. Rory became very distressed and was difficult to pacify when he was carried back into the house.

> ***'We are still unsure as to Rory's level of learning difficulty but we are asking that he be placed in a special school with specialist staff. We feel this will be more beneficial for his future.'***

6.28 'Jason was diagnosed when he was under 3 years old. It was a terrible shock. However we knew that something was wrong and it was helpful to know the truth. I wanted to know what one thing made Jason autistic. It was so helpful to have someone come to our house and explain what autism was in relation to our child. We received training on how to cope with Jason's most difficult behaviour and our family situation quickly improved. The support services we have received since he was diagnosed have been a lifeline. When Jason went to school the level of support was kept up. He is like a different child now. A light has gone on.'

6.29 Jason received early intervention after an early diagnosis. His family targeted his tantrums and inability to cope outside the home environment as areas of great need for them as a family. The early intervention therapist worked on his sensory needs, his need for routine and on providing him with a visual explanation of his environment. She taught him simple augmentative communication methods whereby he could relate his needs using symbols, rather than be frustrated and display constant tantrums. His family worked hard on the suggested strategies and improvement could be seen almost immediately. On going to school the intervention therapist liaised with the teacher who used similar systems to those Jason was familiar with and developed them according to his assessed needs. The speech and language therapist and occupational therapist worked on his individual educational programme alongside the teacher inside and outside the classroom environment.

6.30 Jason's progress has lead to a placement in a mainstream nursery where the teacher had experience of teaching another pupil with ASD and has had access to a little training. He is supported by the ELB advisory service for autism who will help him with transition into year one. Jason is enjoying and benefiting from his experience in the pre-school setting.

> ***'We are so grateful for the support we received. It was useful for us in the home and to our extended family. Jason is a different child. He has moved to a mainstream nursery placement now and is very content.'***

Range of Provision: Views from Pre-school Settings

6.31 Submissions from pre-school teachers, parents and voluntary bodies highlight the following weaknesses in provision for children in the age range 3 to 4 years:

- planning for pre-school services for children with autism is cursory, generally uncoordinated, inconsistent, and ill-equipped to meet the needs of an increasing ASD population. Arrangements to direct provision are not considered adequately within a policy framework;
- there is insufficient guidance from either the Department of Education or the ELBs to promote good practice;
- diagnosis and assessment procedures vary greatly from area to area and between education and health;
- there is not enough training available to nursery staff, and parents, to address the needs of children with ASD, and to skill staff in an appropriate range of intervention strategies;
- there are inadequate resources, including staffing, allocated to meet the demand;
- there is inadequate home-based support;
- there is no guaranteed support for ASD pupils transferring into school settings at year one;
- there is evident inconsistency within and across the nursery education services;
- ASD advisory support service staff cannot provide an adequate service to nurseries due to their rapidly increasing caseloads.

6.32 The teachers and pre-school staff interviewed as part of the Task Group research expressed anxiety about their ability to meet effectively the needs of pupils with ASD, with limited or no training. Many teachers gained their knowledge through books and documents available on the Internet and through contact with the PAPA charity.

6.33 Those teachers who had previous experience of teaching pupils with autism demonstrated more confidence and could discuss a range of strategies based on personal practice and knowledge of pupils' ASD. The Task Group acknowledges the commitment of teachers, many of whom are cited in the parental submissions as highly skilled and committed. However, to extend their levels of competence, it is accepted that further training would enhance their current good efforts. They would feel more confident in preparing comprehensive education plans addressing the individual needs of children with ASD and in providing appropriate access to the pre-school curriculum. Many submissions indicate the need to ensure that the curriculum content of the pre-school programme is accessible to the child with ASD. Their individual needs should be addressed early on in their school experience in order to facilitate future mainstream inclusion as far as possible.

6.34 The teachers surveyed reported particular difficulties providing education for pupils with ASD and severe challenging behaviours, particularly in group settings such as story time or outdoor activities. Many teachers found that the pupils seemed isolated in classrooms, in that they could often tolerate playing at the same table as another child but had difficulties sharing, waiting and turn-taking. Consequently they were unpopular with other pupils and extremely difficult to manage within a whole class setting. Dealing with these behaviours proved time-consuming for teachers and this, they felt, had a detrimental effect on the other pupils in the class. Wing (1994) points out that children of pre-school age can experience severe problems adjusting socially because of the constant unfamiliarity of the child with his social environment.

6.35 These situations are extremely challenging for parents and teachers and make demands on all to have appropriate training and experience in dealing with behaviour, shaping the child's positive responses and in developing their social understanding. Teachers indicated that present staffing ratios are not sufficiently flexible or adequate to enable them to address the needs of children in their classrooms with ASD. The Task Group considers that the issue of challenging behaviour is an important one which raises concerns with regard to integration, safety, staffing ratios, placement and curriculum. This issue is dealt with in more detail in Chapter 10.

6.36 Assessment procedures caused concern among nursery and pre-school teachers. Frequently, pupils with ASD did not respond well to typical modes of assessment and might not perform well. However, during the normal routines of the day, teachers observed many of the pupils demonstrating high levels of skill in a wide range of curricular areas. Teachers often felt that they were unable to motivate the child constantly as it was evident that many of the pupils had pockets of ability which seemed to remain untapped. Educational psychologists also reported having difficulties in persuading children with ASD to attend consistently to a task, thus making some aspects of assessment difficult.

6.37 The inspection evidence, from nursery provision, indicates that the support for special educational needs provided by ELBs varies from board to board; in some boards the evidence is that there is inadequate additional classroom assistance. There is also evidence that the Boards' Curriculum Advisory and Support Services (CASS) provide a satisfactory amount of in-service training on general special educational areas which includes some specific advice on autism. The range of training varies across the boards.

6.38 Staff in voluntary and private sectors expressed the difficulties they experience accessing support to meet the needs of children with autism. They pointed out that training is intermittent and often expensive, particularly in the case of TEACCH and PECS training. There is certainly a gap in the training for staff and the professional support available. Consequently children with ASD can be misunderstood as presenting with behavioural difficulties only.

6.39 The involvement of parents in pre-school programmes varies across the pre-school services yet research suggests that their involvement is critical to positive outcomes for the child. Most intervention approaches stress parental involvement and regard parents as co-therapists in the education of their child. Families with a child with ASD generally experience increased levels of stress and significant disruption to their lives. They require particular help with their child's communication and functional living skills. (Schopler and Mesibov, 1984). In Northern Ireland, more parents wish to be part of the intervention for the child with autism and it is common to find parents actively exploring the Internet for information, joining voluntary groups and participating in individual programmes designed for their child (eg ABA). The Task Group commends the development of improved parent/professional collaboration and regards such partnerships as central to pre-school intervention.

6.40 In summary, the ASD provision at pre-school/nursery level across the ELBs is insufficient, patchy and of variable quality. Quality of provision is dependent upon geographical location, training available and the numbers of specialist HSS and ELB staff employed to help meet the individual needs of these children. There are examples of integrated practices; however, it is more common to find that provision is far from ideal. Parents are frustrated by ignorance in schools, lack of resources and inconsistency among professionals. They identify problems from the point of diagnosis, through to recommendations for intervention and on into nursery and playgroup placement. Overall the needs of the majority of children with ASD at nursery level will be best met through partnership with parents and cross-agency work designed to support families and pre-school providers. The most successful practice is likely to be flexible and developmental and designed to encourage the inclusion of the child with ASD into a school setting. The child's needs arising from the ASD should continue to be met together with their social and academic needs in an integrated setting as far as possible.

MODELS OF BEST PRACTICE

6.41 Evidence from ETI 2001 inspections of pre-school services indicates that pre-school provision for special educational needs is satisfactory or good. The inspections of pre-school provision have identified a few examples of poor practice, but overall indicate that the majority of nursery schools:

- identify special educational needs early and make suitable provision for children, often liaising closely and effectively with other agencies;

- draw up education plans and keep good records of children's progress;
- involve parents well.

6.42 The inspections revealed examples of excellent practice which were characterised by:

- each member of staff recognising and appreciating the needs of children with special educational needs;
- the co-operation of other professionals in this aspect of their work;
- a short daily session of individual teaching closely matched to the special educational needs of the children;
- access to appropriate training and support from the board's CASS service.

6.43 In a small number of pre-school settings, where the quality of provision attained high quality, the needs of children with ASD were well met; these examples, however, were not commonplace. It is the Task Group's conclusion that the practice of placing pupils with ASD in mainstream nursery schools and playgroups, with little or no support or advice for the teachers and classroom assistants, does not ensure that the pupils' needs can be met effectively. Children with ASD, in such instances, may miss out on the contribution which effective early intervention can offer. It is, in such circumstances, vital that current provision should be reviewed and improvements set against acknowledged models of good practice.

6.44 In doing so, there is clearly the need for a structure which reflects the views of professionals and parents and provides a range of services for the education of pre-school children with ASD. The services should include:

- early assessment by a multi-disciplinary team, involving parents;

- an individual education plan which directs intervention;
- integrated nursery/pre-school placement;
- specialist nursery/pre-school provision;
- access to specialist ASD support and advice;
- access to therapy services;
- home-based programmes, reflecting the child's needs over time and parental wishes;
- planned transition from home to nursery or playgroup and transition to year one.

6.45 Jordan (2000) suggests that the ideal nursery/pre-school provision is a specialist class on site within a mainstream nursery or primary school where the child could receive part-time support complemented by home support. The class would enrol 5 children with staffing consisting of a teacher, part-time speech and language therapist, part-time occupational and/or physiotherapist, music teacher and nursery nurses providing 1:1 staff:child ratio. NFER (2000) describe the various models across the LEAs in England and pose a number of questions to inform decisions about provision including the issues of specialist or outreach support, funding for Lovaas programmes, priority at early intervention or at secondary level, inclusion versus special provision, inter-departmental liaison and resources.

6.46 The Task Group considers that each board should develop its own provision according to its relative needs and structures and in response to the principles identified in this report (Chapter 3), but makes a strong case for an ASD Pre-school and Early Intervention Service in each board underpinned by a written statement of policy and provision, and indicating guidance on how provision can be accessed.

CHAPTER 6

NURSERY AND PRE-SCHOOL

RECOMMENDATIONS

Recommendation 6(i)

The Task Group recommends that the Department of Education should ensure that ELBs, Trusts and voluntary organisations significantly develop services for pupils of nursery school age so that they include the following features:

- early assessment and regular review by multi-agency, multi-disciplinary teams involving parents;
- access to suitable mainstream nursery/pre-school placement;
- access to specialist nursery/pre-school placement if required;
- provision of a comprehensive and adequately resourced programme by trained staff, implementing an individual education plan which addresses the child's needs and maximises educational and social inclusion;
- access to appropriate levels of training for all staff - the training needs of staff will vary according to circumstances - the training available should match their identified needs;
- provision of educational advice, training and support from an adequately resourced ASD Specialist Service, to include help as required from appropriately trained and supervised classroom assistants;

- access to therapy and advice from professionals allied to medicine, to include support with the development of the child's individual education plan;

- carefully structured and adequately resourced programmes to ensure smooth transitions into the nursery or playgroup and on into primary education;

- home-school programmes which encourage the full involvement of parents.

Recommendation 6(ii)

The Task Group recommends the revision of current admissions criteria for nursery schools to ensure that children with special educational needs, such as ASD, are given priority.

CHAPTER 7

PRIMARY PROVISION

This chapter reviews the educational arrangements made for pupils with ASD in Key Stages 1 and 2 (age 4 to age 11). It considers issues arising from teaching pupils in mainstream schools and in special provision for pupils with moderate learning difficulties and other difficulties. Provision for children with severe learning difficulties is considered in Chapter 9.

Introduction

7.1 The SEN Code of Practice (1998) encourages greater levels of integration and inclusion of children with special needs into mainstream educational settings.

7.2 Children with ASD attending mainstream schools bring individual challenges and rewards to the classroom environment. The issues highlighted in this chapter arose in interviews with teachers working in ASD support services throughout each ELB and with special educational needs co-ordinators, class teachers, Vice Principals and Principals in primary schools and schools for pupils with moderate learning difficulties. Further information was gained from parents who responded to questionnaires seeking their views on current provision for their children.

Current Support

7.3 At present pupils with ASD attending their local primary school receive a variety of types of support depending on their needs and the availability of services. This support can consist of classroom assistance, individual counselling, advice to teachers and parents and flexible arrangements to promote learning and access to the curriculum. In some schools, adjustments are made to the curriculum and emphasis is placed on the social and emotional needs of the individual with ASD. Many schools endeavour to provide supportive environments, supervision during free time and appropriate arrangements to enhance the pupil's integration and sense of security and well-being.

7.4 In all ELBs it is often the case that pupils with ASD are provided with a classroom assistant. Usually the assistant is recruited by the school and paid by the ELB. In some cases the assistants are recruited to the ASD support service and deployed by them to schools as indicated by the assessed needs of the child. This latter arrangement makes it easier to ensure the classroom assistants are properly trained and are supervised by a teacher with specialist expertise. In such cases also the assistants may be deployed at Code of Practice Stage 3, without the need to wait for a statement of special educational needs.

7.5 Where pupils attend schools for pupils with moderate learning difficulties (MLD), classes are small and the adult:pupil ratio is high. It is common for there to be a classroom assistant available for support. Support on site frequently includes access to speech and language therapy and sometimes also occupational therapy. The small numbers in the class and the emphasis on routine and structure often enhances the pupil's school experience. However, teachers expressed anxiety at having children with ASD in their room as many felt inadequately trained and inexperienced in meeting the needs of pupils with ASD.

7.6 Pupils with ASD in some ELBs may attend Speech and Language Units, but in some boards the admissions criteria for these units specifically exclude pupils with ASD.

7.7 Cedar Lodge school in the Belfast Board is the only special school in Northern Ireland for children with medical problems which impact on their educational progress. An increasing number of pupils coming to the school have ASD.

7.8 Support is available for mainstream primary-aged pupils in each ELB from ASD support staff but this type of support is not always available to MLD schools. It may be that ELBs consider that MLD schools do not need this support because they have a high adult:pupil ratio, but the Task Group finds that many teachers in MLD schools have not had the training and ongoing support that is necessary for them to develop adequate expertise in teaching children with ASD. In one ELB access to ASD support is available only to pupils with a statement of special educational needs.

Belfast Education and Library Board (BELB)

7.9 The Oakwood Support Team at present consists of 2 support teachers and 5 classroom assistants. This service is available at Code of Practice Stage 3, ie a statement of special educational needs is not required. The team supports pupils at Key Stage 1 and 2, providing advice and training when required. A classroom assistant from the team can be assigned to pupils for varying amounts of time according to need. Some pupils with ASD are supported by the outreach services from Harberton and Clarawood schools.

North Eastern Education and Library Board (NEELB)

7.10 In NEELB the ASD support service consists of a seconded field officer who supports pupils at Code of Practice Stage 5 (ie pupils with statements of special educational need) and provides training and advice to schools throughout the ELB as required.

South Eastern Education and Library Board (SEELB)

7.11 In SEELB the ASD support service consists of a Senior Advisory Teacher and an Advisory Teacher. They provide training for individual schools from nursery through to post-primary including special schools and units provision. They also provide training for parents and professionals, often in conjunction with colleagues from HSS, and support for pupils on an individual basis.

Western Education and Library Board (WELB)

7.12 In WELB the ASD support service team consists of a teacher and a classroom assistant providing training and advice to primary and post-primary schools as required, mainly in the Foyle Trust area. Another advisory teacher will take up post in early 2002 and will support schools in the more southerly parts of the board area.

Southern Education and Library Board (SELB)

7.13 In SELB the ASD support service consists of an Assistant Advisory Officer (AAO) and a peripatetic teacher. The AAO provides training to schools and works with post-primary pupils on an individual basis. This person also participates in 2 multi-agency special assessment clinics. The peripatetic teacher supports pupils in nursery, primary and post-primary sectors.

7.14 More generally, many of the teachers involved in support services participate in the TEACCH strategy for Northern Ireland, facilitated by PAPA. The intended outcome is the creation of a team of TEACCH trainers able to carry out cost-effective feasible training. Four ELBs participate in the Northern Ireland TEACCH strategy. In SEELB the advisory team are an integral part of TEACCH training facilitated by their board in conjunction with the Down Lisburn Trust.

7.15 ASD support services may also work in schools for children with severe learning difficulties at times, providing advice and training. However most do not view this as a priority as expertise is already available from a number of teaching staff employed in these schools.

7.16 Teachers in schools and units for children with MLD and other problems have had fewer opportunities for training in ASD. Many are less well equipped than teachers in SLD schools to make policies for pupils with ASD or to create individualised education plans for them. In SLD schools approximately 20% to 25% of pupils have ASD. The proportion is much lower in other special schools and units and in mainstream schools.

7.17 The main remit of the advisory staff is to support pupils in mainstream education. Their caseloads throughout each ELB are increasing. Their job descriptions may include: training for parents, teachers and classroom assistants; meeting parental needs; contributing to diagnostic services; working alongside voluntary services and keeping up-to-date with local and international developments in service delivery. Although essential, this work is leading to great demands on time and the dilution of services to the pupils themselves.

Emerging Issues

7.18 The Task Group has identified a number of issues and perceived gaps in provision for primary-aged pupils. These point to the need for ELBs and Trusts to review provision and put in place more effective structures and strategies in order to ensure that “autism friendly” environments are provided in mainstream and special schools and units. These issues are listed below and considered later in greater detail:

- teacher anxiety about their ability to educate children with ASD;
- teacher concerns about coping appropriately with behavioural difficulties associated with ASD;
- lack of understanding of ASD by teachers, some of whom have little or no ASD training or empathy;
- the lack of training of teachers and classroom assistants;
- irregular access to specialist ASD teachers/advisers;
- poor emphasis, within the curriculum, on the social and emotional needs of children with ASD and their lack of friendships;
- few curriculum guidelines directing ASD provision;
- weaknesses in inter-agency co-operation;
- inconsistency of support from Trusts;
- lack of access to speech and language therapists and occupational therapists;
- the generally poor co-ordination of therapies with teaching programmes;
- the lack of after-school and holiday time support;

- the difficulties experienced by siblings and the family;
- in some ELBs the slowness of the statementing process and policies which prevent access to provision unless pupils have statements (ie have reached Code of Practice Stage 5);
- the lack of flexible placement arrangements to meet needs (eg the fear that once placed in special provision return to mainstream is unlikely);
- weaknesses in home/school liaison;
- the difficulties of transfer from pre-school provision to primary school;
- the difficulties of transfer from the primary sector to post-primary.

7.19 A recent survey by the Education and Training Inspectorate focusing on the provision for pupils with Asperger syndrome in primary and post-primary schools 1999-00 found that the quality of provision varied considerably:

> ***'In general, it ranged from satisfactory to good; in a few instances, the practice observed was of excellent quality and in one case the needs of the pupils were not being met.'***

7.20 The survey found, and discussions with teachers confirmed, that teachers' anxieties are increased by the pressures arising from co-ordination of teaching programmes and infrequent, and often casual, contact with numerous education and health professionals. Many teachers were unclear as to how to refer a pupil with Asperger syndrome for additional assistance, and equally unsure of the type of help a child may require. Teachers' difficulties were compounded by the fact that in many cases there is only informal inter-agency co-operation. The ETI survey report states,

> ***'There is a need to ensure that the pursuit of consistency within the area boards should be mirrored by a similar development across the boards and between Health Trusts and the area boards.'***

7.21 Several submissions from parents mentioned the delay in receiving support following referral for assessment. Most pupils with ASD do not cope well in school without additional adult support. In some boards this can usually only be secured through the issue of a statement. The statementing procedure is a lengthy process, sometimes taking more than 6 months. Even before the statementing procedure begins children may have to wait for a considerable period for an informal (Stage 3) assessment to be completed. In such circumstances, parents are frequently frustrated and angered since such delays prevent the early intervention which is considered crucial to future development for children with ASD.

7.22 There is a general concern among parents that placement may be final and that inappropriate placement is difficult to alter. Concern about the annual review procedure, and the potential of a flexible placement such as temporary attendance in a special class or school becoming a permanent set-up, underlies parental anxiety. Parents need to be better informed of the statementing process and the purpose of the annual review as a mechanism to provide a continuum of provision across a range of different settings with an emphasis on integration and inclusion.

7.23 A very effective model, providing a continuum of provision, has been created in a Primary School in the SEELB area. The Speech and Language unit in this school consists of 2 teachers educating pupils at Key Stage 2. There are 14 boys in the unit, 8 of whom have ASD. The unit seeks to improve the pupils' skills in communication and social interaction and their awareness of appropriate behaviour. It also aims to increase their independent working and living skills. Every opportunity is taken to integrate the pupils into general school life and regular liaison between home and school is a valued feature of the unit. The unit is centrally positioned within the school and it provides easy access to genuine, realistic integration opportunities. A speech and language therapist divides her time between this unit and one other in the area.

7.24 The training of staff is identified as a priority issue in meeting the needs of pupils with ASD. The teachers interviewed felt that training needed to be available as a prerequisite to teaching pupils with ASD. Teachers felt frustrated in that training is difficult to access and expensive. The ASD advisory services offer in-service training courses but they are insufficient to meet the demand. Teachers felt that whole-school training on a basic level would be very useful to ensure that all staff members were aware of issues involved in helping a child with ASD integrate into school life.

7.25 Parents and teachers highlighted classroom assistant training as essential. Without training the assistant can misunderstand the pupil, leading to situations where the child becomes over-dependent or starts to resent the help given. Training needs to be available covering the nature of autism and specific strategies for dealing with pupils at difficult times such as whole-class or group lessons. Assistants need to be aware of how to help the pupil in dealing with the social demands of break and lunchtime and how to organise their belongings to cope with the demands of a school day. Presently, training for classroom assistants is difficult to access and often informal. ELBs need to ensure that training for assistants is appropriate and accessible. The Task Group notes that many assistants are not linked to ASD support services, but are recruited by individual schools. Assistants who are members of ASD support services appear likely to have much better opportunities for appropriate training, advice and supervision.

7.26 One in-service training courses booklet examined for the purpose of this report contained details of 155 courses, only 3 of which were related to issues of ASD. Most primary in-service training booklets did not include information on any of the courses provided on ASD.

7.27 The behaviour of children with ASD emerged as a recurring theme in interviews with professionals in schools. There is no doubt that meeting the needs of a pupil with autism can be extremely challenging. Managing pupils effectively often requires changing traditional approaches to teaching, learning and discipline. Teachers noted that they often had to make differences in their treatment of the pupils with ASD in order to accommodate their needs and that this action often led to resentment amongst the other pupils. Lack of understanding from staff and peers compounded the difficulties experienced in managing behavioural issues.

7.28 Specific behavioural characteristics highlighted by teachers included:

- aggressive and odd behaviours;
- difficulty understanding and following rules;
- lack of motivation;
- organisational difficulties;
- difficulties with concentration;
- rude and outspoken remarks;
- violent outbursts.

7.29 Teachers felt that unstructured times were often most difficult for these pupils.

7.30 Parents and teachers were very concerned about bullying in relation to pupils with ASD. The pupils' different styles of thinking, learning and behaving make them very vulnerable and it is feared that pupils with ASD may become more socially isolated and vulnerable as they get older. The school environment should be safe. Appropriate policies and strategies should be employed to prevent bullying and to deal effectively with it when it does occur. Schools need support and advice from ELBs on appropriate policies and strategies, such as some of those mentioned in the paragraph below.

7.31 Teachers recognise that pupils with ASD have particular need for help with social and emotional needs. Many feel, however, that they lack expertise and are unsure about how to address the issues arising as a result of the pupil's lack of social understanding. This has implications for training and support for teachers in using methods such as circle time, role play, social stories and comic strip conversations, and in developing 'buddy' or mentor systems and 'circle of friends' approaches for use within schools. Social skills need to be addressed from Key Stage 1 in teaching the child with ASD to, for example, take turns, share, wait, ask to use other people's possessions and to share their own willingly. The child is also likely to need guidance on how to join a group, and to begin and maintain friendships. The ETI Asperger syndrome survey (1999-00) found that where school had access to ASD support services from the ELBs,

> ***'Attention to social and behavioural issues was more marked… education plans included targets for encouraging positive classroom interaction, and the schools reported improvement in the pupils' social behaviour over time.'***

7.32 Teachers and parents indicate that pupils can appear to cope well with the school situation, but at home, their behaviour is often very different. Some parents expressed concern that their child spent long periods of time in the bedroom finding solace in a current obsession, or would get upset or aggressive very easily after school. It would seem that some pupils become increasingly stressed during the day and then react adversely when they reach the safety of their own home and family.

7.33 It is important that teachers should include targets for social understanding and behaviour in the child's individual education plan (and therefore reflect the child's autism), in addition to targets for academic tasks. Speech and language therapists are specifically trained and skilled at assessing and teaching the use of social skills. Educational psychologists and other members of Behaviour Support Teams in the ELBs also have expertise in assessment and teaching of social skills. In one inter-disciplinary project the Task Group notes that educational psychologists and social workers are collaborating in a social skills training project with pupils who have just transferred to post-primary education. There are many resources available for teachers to access, but most said they would welcome support in setting specific social and language goals.

7.34 Teachers also need assistance in assessing the child's expressive and receptive language abilities and in setting up alternative communication systems when necessary. The report from the Working Group on the Provision of Speech and Language Therapy Services to Children with SEN in England (November 2000) incorporates this view:

> ***'Therapy for children of school age is best carried out collaboratively within the school context…assessment, diagnosis and therapy should all be carried out in conjunction with teachers and parents/carers.'***

7.35 The report further states that the educational context should inform provision. The Task Group considers that speech and language therapists should play a central and consistent role in the education of children with ASD. However, speech and language therapy managers point out that they do not have enough therapists to carry out sufficient school-based multi-disciplinary work. At the instigation of the Minister there has been a recent increase in the number of therapists being trained from 24 to 30. This may still not be sufficient to meet demand.

7.36 Pupils with ASD often have difficulties with motor co-ordination and are likely to have heightened or impaired sensory awareness. Motor problems often lead to difficulties with writing and the presentation of work and such problems may in turn lead to problems of self-esteem, motivation and conflict with teachers. Sensory awareness problems may affect many areas of the pupil's life and inhibit the child's ability to concentrate, sit still, and take part in everyday activities such as eating, dressing, work and play. It is vital that pupils in mainstream primary schools have access to an occupational therapist skilled in addressing these issues. Occupational therapy managers feel that this would be a useful approach to therapy, but state that clinical caseloads are very difficult to manage. The numbers embarking on University courses total 50 per year and all are given general training with sensory and motor issues included. There are relatively few jobs in paediatrics, however, so trainee therapists tend not to specialise in this area. There are, as a result, very few qualified occupational therapists who have an interest in ASD.

7.37 Professionals and parents alike recognise that there is often weak co-ordination of services from education and health and social services within the school setting. The increasing involvement of educational psychologists and advisory teachers in multi-disciplinary clinics does facilitate better communication between the clinic and the school. However, it remains difficult, while therapists remain primarily clinic-based, for them to have sufficient influence on the individual education plan for the child.

7.38 Often schools and supporting professionals must operate in response to situations as they arise. Comprehensive forward planning, however, is essential to ensure that appropriate arrangements are in place to support children with ASD at critical times so that crises may be avoided. It is vital for example that the child and family and the receiving school are prepared in advance for the arrival of the child into year one or into first form of a post-primary school. The Task Group is aware of examples of year one teachers being provided with training and support by the ELB advisory staff or educational psychologists in anticipation of the arrival of a child with ASD into their class. The Group commends this practice and recommends that it should become the norm.

7.39 It is commonly the case with children who have ASD that changes in routine lead to difficult behaviour. Parents often find that the child with ASD reacts negatively to school holidays, and in some cases the outcome may be very challenging behaviour at home and a great deal of stress for the family. There is a need in many cases for provision during holidays, but it is not clear whether the responsibility for making such provision should lie with the ELBs or with the Trusts. Collaboration between ELBs, Trusts and voluntary agencies may bring about a resolution of this problem.

Features of Good Practice

7.40 The Task Group contends that Key Stage 1 and 2 provision for children with ASD should be:

- flexible;
- differentiated;
- individually planned and resourced;
- inclusive;
- functional;
- structured;
- supported.

7.41 The Task Group considers that best practice should be underpinned by 3 crucial components:

- a whole-school ASD approach, including a range of provision and inclusive ethos;
- staff training and commitment;
- close links with parents as educators.

7.42 Effective whole-school practice includes informing all staff of the nature of the child’s difficulties and making them aware of strategies to help the child with ASD integrate into the school environment. Effective and positive educational experiences for the child with ASD depend on the staff having an understanding of ASD and how it relates to the individual child in their classroom. The long-term implications of the condition must be considered and short-term targets should be included in the individual education plan. Arrangements to help the child transfer from nursery or playgroup into year one should be well established and shared with the parents. A potentially difficult time for pupils with ASD is transferring to post-primary provision. The primary school should consider this in advance and make plans, along with ELB support staff, to ensure a smooth transition.

7.43 The Task Group, in making its judgements, considers the following main characteristics as central to a school's planning for effective practice:

- staff knowledge and expertise;
- access to ancillary support as indicated in the child's statement or IEP;
- access to peers of similar age and ability;
- curriculum flexibility matched to the child's strengths and interests;
- parental involvement.

7.44 Schools offering added value for children with ASD will, in the Task Group's view, have classroom assistants with appropriate training, and nominate an ASD teacher co-ordinator to act as an advocate for these pupils. This person, who in many cases may be the SEN co-ordinator, should initiate and implement a whole-school policy and arrange provision, including a home support programme. Teachers should endeavour to create co-operative learning activities using the strengths of the child with ASD as a central focus of the task. In all instances the staff should foster involvement and actively plan opportunities to exploit possible group or paired work.

CHAPTER 7

PRIMARY PROVISION

RECOMMENDATIONS

Recommendation 7(i)

The Task Group recommends that the Department of Education should ensure that ELBs, Trusts and voluntary organisations significantly develop services for pupils of primary school age so that they include the following:

- early assessment and regular review by a multi-agency, multi-disciplinary team involving parents;
- access to suitable mainstream placement;
- access to special unit placement when required, and for as long as required, subject to regular review - the needs of some pupils with ASD may be met in MLD units or Speech and Language units but some pupils may require placement in a unit specially designed to meet the needs of pupils with ASD;
- access to special school when required, and for as long as required, subject to regular review - the needs of some ASD pupils may, for example, be met in MLD schools or in schools which cater for children with communication difficulties or medical difficulties;
- provision of a comprehensive and adequately resourced programme by trained staff, implementing an individual education plan which addresses the child's needs and maximises educational and social inclusion;

- access to appropriate levels of training for all staff - the training needs of staff will vary according to circumstances, and the training available should match their identified needs - staff in special schools and units for children with MLD, speech and language problems and health problems will have particular need of training since they work frequently with pupils with ASD;
- provision of educational advice, training and support from an adequately resourced ASD support service, to include help as required from appropriately trained and supervised classroom assistants;
- access to therapy and advice from professionals allied to medicine, to include support with the development of the child's individual education plan;
- carefully structured and adequately resourced programmes to ensure smooth transition into year 1 and on to post-primary education;
- home-school programmes which encourage the full involvement of parents;
- summer schemes appropriate to the needs of ASD children.

CHAPTER 8

POST-PRIMARY PROVISION

This chapter describes the common issues arising when a pupil is in post-primary education. The section will highlight examples of good practice, and make recommendations for improvement set in the context of current research.

Introduction

8.1 The issues relating to post-primary provision are similar to those highlighted in the primary section. However, the post-primary environment brings new challenges to the pupil with ASD. The social demands are increased due to greater pupil numbers and the constantly changing set of social principles that most pupils in their teens automatically acquire. Organisational demands are also highlighted due to the sheer size of the school. Having to move to different classes can mean additional anxiety for pupils with ASD.

8.2 The information for this chapter has been gathered by interviews with pupils, teachers, parents, special educational needs co-ordinators (SENCOs), educational psychologists and ASD support teachers working in the post-primary sector. Additionally, the data includes the opinions and experiences of a number of Health Service professionals working with adolescents with ASD.

Current Issues

8.3 Although diagnostic clinics are becoming established throughout Northern Ireland there are many pupils who have missed the benefits of early diagnosis and may only gain a diagnosis in their post-primary years. Teachers and Health Service professionals consider that in these instances the behavioural, social, and emotional difficulties faced by these pupils are more marked. The pupils are likely to have been misunderstood, as their additional needs cannot have been understood or adequately met without a defining diagnosis. Most of the pupils have the disadvantage of having to come to terms with adolescence and with a diagnosis of autism or Asperger syndrome and the implications of that on their lives. The more extreme difficulties displayed by many pupils with a later diagnosis serve to highlight the importance of an early diagnosis and intervention programme to ensure that difficulties are addressed at a young age. There is more likelihood that the child with ASD will then be better equipped to deal with the demands of post-primary education and the later demands of independent living. Raising awareness of autism and the associated features through leaflets, booklets and media coverage would help teachers and parents to recognise the difficulties at an early stage in the child's life.

8.4 Teachers and pupils in the post-primary setting interviewed as part of the work of the Task Group identified a number of demands which arise from the more complex organisational and social setting of the post-primary school. These demands include:

- accessing the correct book for each subject from day to day;
- organising loose worksheets and folders;
- managing a musical instrument;
- sorting out PE kit;
- using locker systems appropriately;
- moving from class to class through the noisy and less structured environment of school corridors;
- coping with teachers' expectations, which are often not made explicit enough;
- being understood by teachers and peers;
- having a growing realisation that they are different.

8.5 Frequently, the pupils with ASD could appear outspoken and rude in class and had difficulties with turn-taking, waiting and sharing. The teachers reported behaviours which they interpreted as attention-seeking and disruptive behaviours, which delayed the progress of others in the class.

8.6 Pupils and teachers remarked that physical education was often a problematic subject. Pupils found it difficult to work in a team and to take account of other pupils' points of view. They had difficulties remembering and adhering to rules; their spatial awareness was often poor. They also had difficulties in understanding competitive games. The source of these difficulties lies in the associated features of ASD but may be compounded by the lack of opportunities for informal practice in team games. Typically developing pupils play games in the playground whilst children with ASD often remain isolated at these times and do not make use of the opportunities to learn the rules of play.

8.7 Handwriting and the presentation of pupils' work were thought by the teachers to be of poor quality in comparison to the pupil's academic ability. Teachers often misunderstand this as a behavioural problem rather than as a possible effect of having poor motor skills and/or poor muscle tone. In addition, having to complete work at speed is often a problem for pupils with ASD, as many tend to get tired easily and often need to take breaks before finishing a piece of work.

8.8 Homework is an issue with teachers, parents and pupils. The pupils have problems noting their homework correctly or spend hours at night time trying to complete it. Pupils with ASD may perceive study as an activity rightly based in school and may not understand why it should be done at home.

8.9 Teachers were also concerned that pupils' exam techniques were often poor. They report that pupils know the answers but tend to miss the main point of the question. This was a common problem in whole-class lessons, where the pupil would become very interested in an irrelevant detail often missing the main teaching point altogether. Frith (1989) refers to this as 'Central Coherence Deficit.' Simple solutions such as a system for highlighting important points, plots, formulas or quotations can help solve these problems. However, teachers need to be trained in ASD and the implications for learning in order to use such strategies effectively.

8.10 In addition, examination time brings the added pressures on the pupil to do a greater volume of work at home. This task becomes increasingly problematic at GCSE level when the course work required is practical and involves applied knowledge. Pupils with ASD need to have very clear guidelines as to when work must be completed. A study guide for planning revision should be provided for and discussed with them. Coping strategies may need to be made explicit if changes in their revision timetable occur. The pupils may need special arrangements for completing exams such as extra time, using word processing or having an amanuensis made available to them. They may also benefit from guidance on following examination instructions and allocating appropriate time to different parts of the examination. These interventions are not always known by or used consistently by teachers and staff working with pupils with ASD.

8.11 An acute problem for pupils in the post-primary environment is bullying. Typically developing pupils at this stage do not like to include people who are ‘different’ into their social circle. Pupils with ASD are particularly vulnerable because of their inabilities to understand the implications of the social setting and often feel insecure as a consequence. Many pupils understand threats and name-calling in a literal manner. They get very anxious about how they are being treated and are unable to defend themselves in these situations. This makes bullying a particularly serious issue for pupils with ASD. Teachers need to be aware that bullying can be quite subtle and is likely to take place in class and at unstructured times, in the corridors or at break and lunchtime. In most schools there is little awareness of the impact the environment makes on the lives of pupils with ASD and in most instances, little is done to assess the environment of the school as a factor in the challenges facing them. Pupils may need assistance at these times, perhaps with alternative activities being provided.

8.12 All pupils with ASD differ in their personality and temperament. Some find the demands of school very difficult to cope with and withdraw, keeping their anxieties hidden. Other pupils display aggressive behaviours, misunderstand the notion of being popular and become disruptive and violent within the home and school environment. These anxieties can lead to school refusal or phobia. Depression can develop early on in their lives and, according to health professionals, psychotic behaviours can occur leading at worst to being admitted to an institution or to suicide (Fitzgerald and Matthews, 2000).

8.13 A number of pupils complained that when their diagnosis was given to them people began to treat them in a childish manner as if they were not bright. One pupil asked:

> ***"Why does everyone treat me like a baby?"***

8.14 Another pupil was less able to express specific difficulties experienced in school, simply stating, ***"help me".***

8.15 The visiting ASD service within the ELBs found the above examples typical and commonplace and underline the importance of schools developing a policy to ensure the pupil's needs are clearly understood and responded to.

8.16 Other issues commonly raised by SENCOs and ASD support service teachers and educational psychologists related to difficulties the pupils experience in coping with social and emotional issues. Teachers felt ill-equipped to deal with these issues and requested access to health professionals to help their work with the pupils. The teachers were aware that social skills training would be invaluable for these pupils but were often unsure what this would involve or how to access appropriate training packages.

Current Provision

8.17 Across the ELBs, the range of provision is similar and the allocation of additional resources, including staffing, is usually a response to problems that have arisen rather than as part of a strategic plan and policy directive. Provision includes:

- additional classroom assistants;

- advice from the ASD service;
- input from the Educational Psychology Service;
- access to information and courses organised by the ELBs' Curriculum and Advisory Support Service;
- curriculum modifications and examination support.

8.18 In most responses, it was clear that the level of support was insufficient to effect improvement; principals complained of the difficulties maintaining regular contact with the support services and of the pressures on the service to meet the demands made of it. It emerged from the submissions that appropriate and suitably planned intervention programmes directing individual education plans were available only on a limited basis. In relation to training, the lack of a coherent programme aimed at the post-primary sector is regarded by the principals as a major obstacle to the development of provision in this area.

Models of Good Practice

8.19 ASD support service teachers and educational psychologists found from experience that it was useful for the pupil to have a named adult to talk to at designated times. They also reported that assigning peer mentors was helpful in that other pupils could take care of the pupil with ASD and provide guidance for them in the classroom and particularly during unstructured times such as transitioning to other classes and at break and lunchtimes. One pupil reported feeling safer and less anxious about coming to school when using a mentor system. This system works best when the mentors are informed that the pupils have a diagnosis of ASD and the condition is explained to them. However, the family of the pupil and the pupil have to be in agreement before disclosure. Often pupils have concerns about other pupils knowing. They worry that it may make the school situation worse or lead to further bullying. These factors must be fully considered before intervention.

8.20 Social skills teaching is necessary for these pupils because they do not learn these skills incidentally. There are varying methods of teaching such skills. Social skills groups often bring pupils with ASD together to teach them specific skills in particular areas of difficulty, such as initiating and maintaining friendships. The advantage of this method is that pupils can meet others with interests likely to be similar to theirs; however, the pupils may have difficulties in generalising the skills learned in isolated groups. Mariage et al (1995) propose that programmes should be conducted within the school setting. This may be possible during PSE lessons and would be most effective if educational psychology, speech and language therapists, ASD advisory teachers and class teachers liaised on the content and delivery of the lessons and their application in the wider school environment. Whole-school training is very effective at the transition year when the pupil is changing schools. In addition to this, simple strategies, such as the pupil visiting the school, meeting their teachers and being given a map to help them negotiate the building can make the transition easier for the pupil. Follow-up training is helpful when the pupil has spent a term in the school and the staff and parents are aware of the pupil's unique difficulties. ASD support teachers state that this is good practice but that time restraints and heavy caseloads make it very difficult. Any training programme in the post-primary sector needs to include methods for the teaching of social skills.

8.21 An innovative project is taking place in the Southern Board where a social worker is attached to the school and a social skills training programme is being piloted where the child with ASD is learning skills alongside his peers. Some social workers are gaining expertise in this area and would be useful partners in delivering programmes.

8.22 The Circle of Friends approach (Jones, 1999) specifically targets the needs of the pupil with ASD as the focus of the group; it is designed to help the pupil integrate more easily and has proven to be effective in many school settings (Whitaker et al, 1998). A most effective way of teaching social understanding is to teach the skills in the environment in which they are necessary. This would mean bringing the children with ASD into structured situations in the community. In addition to this some pupils may need one-to-one explanations of appropriate social behaviour and understanding. A designated teacher within school might provide this. Whatever the methodology, it is clear that this is an area which needs to be addressed by health and education professionals working collaboratively.

8.23 Speech and language therapy input is also vital for these pupils. The speech and language therapist can accurately assess their receptive understanding and how appropriately they use their language. They are highly skilled in assessing and delivering social skills training and would be an important asset in devising programmes and ensuring the generalisation of the understanding acquired.

8.24 Occupational therapy is valuable for post-primary pupils in dealing with handwriting and presentation of work and in addressing possible motor or sensory difficulties. Pupils with ASD may require a palm or lap-top computer to help with presentation. Many schools stated that this is difficult to access due to the child not displaying obvious physical disability. Occupational therapy advice would play a useful part in gaining access to this kind of equipment.

8.25 In the course of its deliberations, the Task Group endorses many of the views expressed in the submissions, and suggests that a special resource base option for pupils with high functioning autism or Asperger's syndrome is an important facility which should be considered. One member of the Task Group visited facilities, including a post-primary school, in Cumbria LEA in England, which has established an effective level of provision to support some 15 pupils with ASD. The facility has a number of important strengths which are worthy of note. These include:

- a well-established LEA autism policy;
- ringfenced funding (individual capitation);
- strategic planning;
- comprehensive assessment including risk assessment;
- individual teaching as required;
- individual counselling;

- whole-school training, including accredited training for staff more involved with the pupils;
- an annual dissemination conference to evaluate the provision;
- a developed system of monitoring and evaluation;
- exit strategies to local and specialist FE colleges and training provision.

8.26 It is clear that whole-school approaches to creating an environment in which the child with autism can function is necessary. The ETI Asperger Survey (1999-2000) Report recommends:

> ***"the development of an ethos which favours the needs of pupils with Asperger syndrome."***

8.27 Training is the key to providing positive environments for these pupils. Training programmes need to be available for teachers and classroom assistants. In one ELB's in-service booklet two half-day courses were available on autism out of 129 courses for teachers. Most boards do offer ASD courses but not as part of a strategic training plan.

8.28 Jordan (1996) found, in Scotland, that parents of children at this age often sought residential schooling, concluding that for some children with ASD a range of settings will be needed to meet the various needs of pupils during their second level years.

CHAPTER 8

POST-PRIMARY PROVISION

RECOMMENDATIONS

Recommendation 8(i)

The Task Group recommends that the Department of Education should ensure that ELBs, Trusts and voluntary organisations significantly develop services for pupils of post-primary school age so that they include the following:

- continuing assessment and regular review by multi-agency, multi-disciplinary teams involving parents;
- access to suitable mainstream placement;
- access to special unit or placement when required, and for as long as required, subject to regular review - the needs of some pupils with ASD may be met in MLD units or Speech and Language units but some pupils may require placement in a unit specially designed to meet the needs of pupils with ASD. These units may be attached to designated secondary schools;
- access to special school when required, and for as long as required, subject to regular review - the needs of some ASD pupils may, for example, be met in MLD schools or in schools which cater for children with communication difficulties or medical needs;
- ASD resource bases in schools to support pupils unable to integrate fully into mainstream classes and to provide additional advisory and practical help to all members of staff - such bases should in turn be supported by the ASD support service;

- residential provision for some pupils, which maintains high levels of involvement of parents and staff from the mainstream school and works towards reintegration;

- provision of a comprehensive and adequately resourced programme by trained staff, implementing an individual education plan which addresses the child's needs and maximises educational and social inclusion;

- access to appropriate levels of training for all staff - the training needs of staff will vary according to circumstances, and the training available should match their identified needs - staff in special schools and units for children with MLD, speech and language problems and health problems will have particular need of training since they work frequently with pupils with ASD;

- provision of educational advice, training and support from an adequately resourced ASD support service, to assist post-primary pupils to integrate and benefit from mainstream placement;

- access to therapy and advice from professionals allied to medicine, to include support with the development of the child's individual education plan;

- close co-operation between education and health professionals to ensure that the social and emotional needs of pupils with ASD are jointly planned for within a personal social education programme including individual counselling when necessary;

- carefully structured and adequately resourced programmes to ensure smooth transition into Further and Higher Education, training and work placements;

- home-school programmes which encourage the full involvement of parents.

CHAPTER 9

PROVISION FOR CHILDREN WITH ASD AND SEVERE LEARNING DIFFICULTIES

This chapter considers and reviews the education of children with severe learning difficulties and ASD and makes recommendations for the development of comprehensive provision for this group of pupils.

Introduction

9.1 There are pupils with severe learning difficulties (SLD), who are not designated as having Autistic Spectrum Disorder (ASD) within their statements, but who are regarded as having autism by experienced teachers and principals of special schools. A realistic number of pupils with autism cannot be obtained, therefore, by counting numbers of pupils with autism on their statement.

9.2 In one Education and Library Board, for example, a diagnosis of autism may be made by an educational psychologist but in most boards this is not the normal practice. In some board areas the diagnosis is made by a multi-disciplinary team. Occasionally there is a reluctance by parents to accept a diagnosis of autism. In such circumstances, the term ‘autism’ will not be used in reports or documents, including the child’s statement of special educational needs. Some parents of children with SLD who receive an additional diagnosis of autism tend to disregard the impact of the severe learning difficulty.

Incidence Rates and Projections

9.3 Most SLD schools contacted during the compilation of this report indicated that the numbers of pupils in the lower age group on the autistic spectrum are increasing. In one school, for example, which caters for children in the 3-8 age range, 40% of the pupils have autism.

Another school reports 15 out of 18 infant-aged pupils as having autism. A significant number of schools report approximately 25% of their pupils as having autism. The percentage of pupils with SLD and ASD as reported in the Education and Training Inspectorate (ETI) Survey 1998-2000 is now perceived by schools to be an underestimate.

Current Provision

9.4 The information in this section was gathered by questionnaire from 22 schools for children with severe learning difficulties (SLD). Discussions were also held with a number of the principals of these schools. The ETI report of 1998-2000 on Severe Learning Difficulties was an additional source of information. A scrutiny of relevant literature was also undertaken.

9.5 Presently, all SLD schools have pupils with autism. There are a total of 352 pupils with autism in SLD schools with a further 107 pupils suspected as having autism by their schools although not diagnosed. This indicates a range of 20% to 26% of pupils with ASD attending SLD schools. Most pupils regarded by the schools as having an ASD but without a diagnosis are in the senior age group. The majority of pupils diagnosed with autism are in the infant/junior age group. Pupils with autism are integrated in classes of their peer groups in all SLD schools. In addition 7 schools each have one class exclusively for pupils with autism and 5 schools have more than one class for autism. Most SLD schools run summer schemes for their pupils for between one and 3 weeks during the summer break. The summer schemes are staffed by a core of teachers and/or classroom assistants who work in the schools with additional staffing required in some cases.

9.6 Teaching methods within SLD schools are based on structured approaches. All schools cite using Treatment and Education of Autistic and related Communications-Handicapped Children (TEACCH) methods, 15 schools use the Picture Exchange Communication System (PECS), one school uses intensive interaction (Nind and Hewitt, 1998), and 8 schools report using behavioural analysis for dealing with behaviour problems. All SLD schools have at least one teacher trained in TEACCH methods. Four schools have undertaken training with the Institute for Applied Behavioural Analysis, Donnellan and LaVigna (IABA). One school has a teacher who completed the module on autism with Queen's University, Belfast. Several teachers throughout Northern Ireland have completed the University of Birmingham autism course which is undertaken by distance learning. Successful completion of the one-year course results in a qualification of an Advanced Certificate in Education (ACE), the two-year course gives a Diploma in Special Education on completion; an additional dissertation can be undertaken for a Masters in Education (MEd).

9.7 The schools report confidence in being able to plan for the needs of the pupils with ASD and have established and improved their provision over the past 7 years. The teaching and learning outcomes are of a good standard in the majority of instances (ETI, 2000).

Support to Schools from Education and Library Boards

9.8 Most schools report that they are left to provide for the problem of increasing numbers of pupils with ASD without any additional resources. They feel that the ELBs do not truly appreciate the wide-ranging challenges schools face through this increase. These challenges include: increasing numbers of pupils with autism; increasing parental demands; the need to develop staff expertise in ASD; increasing challenging behaviour; increasing demand for more teaching space; increasing demand for extra staff; increasing demand for specialist resources; and increasing demand on available staff development time.

9.9 Education and Library Boards provide peripatetic support teachers for ASD including one ELB which has in addition an Assistant Advisory Officer for ASD. Schools value the support and advice from the advisers although it is not consistently available. There is a demand for more of this type of provision.

9.10 The Education and Library Boards provide funding to schools for their summer schemes.

9.11 However, funding is not always equitable, with schools of over 100 pupils receiving the same funding as schools with less than

50 pupils. The effect of this is that some pupils are offered one week on a play scheme whilst pupils in other schools are offered 2 weeks.

9.12 One SLD school, with SEELB assistance, has established a unit for challenging behaviour. This is for pupils of secondary age who have behavioural difficulties. The provision is not specifically for pupils with ASD and challenging behaviour but there is some evidence that it is successful for these pupils. A significant factor in the success of this venture is the substantial dedicated, regular input from clinical psychology. Another SLD school, who grouped 8 pupils with ASD and challenging behaviour together, did not find it to be effective and abandoned this strategy. There was no input from clinical psychology services in this example.

9.13 The Task Group validates the contribution made by the clinical psychology service to some schools.

9.14 Input and support from educational psychology services is valued by schools. A thorough assessment with suggestions for teaching and learning strategies is seen as vitally important for children with autism who have uneven profiles of ability.

Support to Schools from Health and Social Services Trusts

9.15 Most schools reported dissatisfaction with the amount and/or type of support available from Health and Social Services. The types of support available are telephone advice, assessment of challenging behaviour and behavioural programmes within a hospital setting. There is a reluctance to allow health staff to work off site in homes and schools in order to help the transition process from one setting to another.

9.16 Input from therapists varies from school to school in time allocation, collaboration and in quality.

9.17 Principals in SLD schools value the support occupational therapy can provide towards addressing the sensory needs of children with ASD. Unfortunately this provision is rarely available in schools.

9.18 Input from clinical psychology and psychiatry is valued where available but the majority of schools report that they receive insufficient support from this sector. Principals point to the need for much more support. The principals consider support as being of greatest value where personnel visit schools regularly and provide detailed reports with suggestions for practice. Further issues identified by the principals refer to:

- the inadequate amount of speech and language therapy received by children with ASD in SLD schools;
- the amount of occupational therapy varies with some schools not receiving any autism-specific input and others getting appropriate input;
- the inadequate availability of music therapy;
- support to families.

9.19 The links between home and school are valued by the school principals and a range of strategies are used including:

- support groups and workshops for parents;
- social work support for families of children with ASD;
- community nurses advice and support;
- voluntary groups, eg Barnardo's, PAPA and PEAT, provide support and training for families.

Current Issues in the SLD Schools

9.20 All SLD schools report that they have pupils with autism who have severe challenging behaviour but who are mostly manageable; a total of 171 pupils throughout the schools. In addition to this, most schools report an increase in numbers of pupils with extremely challenging behaviour which has resulted in an increase in staff injuries, some of them serious. This degree of difficulty concerns a minority of pupils (schools estimate a total of 64), but takes a disproportionate amount of teacher attention and whole-school time resulting on occasion in less than satisfactory provision for other pupils in the same class. This aspect is dealt with in more detail in Chapter 10.

9.21 Some schools report exceptional organisational difficulties arising from lack of sufficient teaching space in which to address the difficulties of pupils with extreme challenging behaviour. Increasing numbers of pupils in some SLD schools have resulted in classes which have unacceptably large numbers of pupils. In one ELB, SLD schools have some classes with 12 to 15 pupils. The inevitable noise and other stimuli in these classrooms can result in behavioural difficulties amongst pupils.

9.22 Staffing, in most instances, is a problem with some pupils needing constant dedicated attention and supervision. Some ELBs provide 1:1 support for these pupils although schools do not regard this as adequate in some instances. One ELB provides 3 classroom assistants for one pupil who is educated in a separate class because of the pupil's challenging behaviour.

9.23 Another ELB provides temporary general assistants for dedicated pupil support. This makes recruitment difficult due to the lower rate of pay. General assistants are usually untrained yet are required to fulfil a consistently demanding role.

9.24 Most schools report that through the use of structured programmes of learning and the use of visual instruction, problems with behaviour difficulties have diminished. Two schools report making significant progress in addressing pupil behaviour problems through the use of structured teaching and behavioural analysis methods.

9.25 One school has undertaken training in restraining techniques for use with pupils. However, the staff do not use this training, regarding it as being impractical to use in the classroom and in conflict with acceptable pastoral care and their school ethos. Research, cited by La Vigna (2001), indicates that pupil restraint exacerbates episodes of challenging behaviour and is inappropriate for the classroom. The school has preferred to develop whole-school positive reinforcement strategies alone, with detailed analysis of the problem behaviour. This is having an immediate and positive affect on the behaviour of the pupils.

9.26 Pupils who have autism and additional psychiatric difficulties may require specialised help from health services. Most schools report a serious lack of support from clinical psychology services. One school principal stated “At present, in our area, this is non-existent”. One school, with ELB and HSS support, has opened a unit attached to the school for senior pupils with challenging behaviour. It has a ratio of 4 pupils to 3 staff with extensive input from a clinical psychologist.

9.27 Behaviour strategies used in schools may fail to bring about acceptable levels of behaviour and more radical strategies may prove necessary. These include suspension, expulsion, and amendment of statements in order to transfer the pupil to an alternative school or to home tuition.

9.28 One ELB is funding a placement in a school in Scotland which caters specifically for pupils with autism and challenging behaviour whilst another ELB is funding placement of a pupil in England. Health Boards have helped in some cases by removing the pupils for assessment and treatment in psychiatric hospitals. There is usually a care plan of residential assessment and treatment followed by a gradual re-entry to home and to school. A major flaw in this system is the lack of structured advice and staff support to schools in order to enable the school to learn and use the strategies being used by the hospital. Liaison is usually casual and not sufficiently focused with a hospital/school/home plan. A further difficulty is the lack of opportunity to generalise new skills and acceptable behaviour learnt by the child or young person into a new environment. Some parents refuse hospital support and when this happens schools are left in a very difficult position. One school principal commented on the dangers to pupils and staff, adding “one extra classroom assistant is not enough for a pupil with extreme challenging behaviour”.

9.29 Some schools report that a shortage of speech and language provision leaves them disadvantaged in addressing one of the core difficulties of autism, that of communication. Speech and language therapists are seen by schools as effective in giving guidance and strategies to staff for working with children with autism as well as assessing the pupil's communication needs and working with the pupils individually.

9.30 Some SLD schools have input from occupational therapists with expertise in working with children with ASD. Sensory difficulties can be significant for some pupils with ASD and detailed assessments and programmes are valued by schools.

9.31 The purchase of equipment to meet the specific needs of pupils with autism can be significant. Screens, for example, are often needed for pupils and cost £100 each. A wider variety of equipment than usual may be needed by individual pupils because of their exceptionally varied ability across a range of skills. One principal suggests that ELBs should give an allocation of money based on the school numbers of children with autism.

Staffing Ratios

9.32 Most schools report that they do not have enough staff to cater effectively for the needs of children with ASD. Where percentages of pupils with ASD within a school are small, schools can manage with the current staff:pupil ratio. However, this is proving very difficult for those schools where a large percentage of pupils have autism. This is because of the need for a higher staff:pupil ratio for these children and the need for class sizes to be kept consistent with pupil need: in some cases schools maintain ASD classes of 4 pupils. The resulting demand for adequate staffing and for classrooms cannot at present be met in some schools.

9.33 The Task Group supports the view that a teacher:pupil ratio of 1:6 with 2 classroom assistants is acceptable.

9.34 Some ELBs have provided classroom assistants or general assistants to help meet the needs of those pupils with autism with challenging behaviour. However, no school reported having extra staff to meet pupil needs arising solely from autism rather than behaviour. It may be that challenging behaviour may not arise if there were sufficient staffing in order to meet the extra needs of these children.

Staff Training

9.35 Education and Library Boards provide some training for teachers who work with children with autism but schools find this training is often inadequate both in frequency and in breadth. Some schools reported that they have very specific training needs which cannot be met by a general course on autism. One school received training in behaviour strategies for pupils with ASD from an ELB behaviour support team member who had experience of teaching these pupils. This was valued by all staff involved because it was based on a detailed knowledge of ASD and clearly focused on practical outcomes in the classroom. Advice from autism support teachers and advisory officers was praised and found to be particularly effective when training was for all members of staff in a school.

9.36 TEACCH training is regarded by some principals to be too sparse in frequency and availability. This is being addressed through the creation of a local training team in Northern Ireland. Several principals commented that TEACCH was the only autism-specific funded training available throughout Northern Ireland whilst a more eclectic choice of training was needed to meet the various needs of pupils with ASD and learning difficulties. It was recognised by school principals that not all pupil needs will be met through the use of one methodology and that a range of strategies and knowledge of different approaches was crucial to the quality of their ASD provision.

9.37 Training by ELBs of classroom assistants is rare but appreciated by staff able to access it. One member of staff commented that ***"it was good to be able to concentrate for a full day on autism and what it means for a child. It makes you appreciate where they are coming from."*** Some schools include their classroom assistants in training days but when staff are employed on temporary contracts they are not paid for training days and subsequently rarely attend.

9.38 Schools are increasingly buying in their own training having identified specific needs. However, their ability to do this is limited, as schools do not have their own staff development budgets. One ELB has funded whole-school training for 2 schools training together in the use of the Picture Exchange Communication System (PECS). This was found to be particularly useful in allowing all teachers and speech therapists in the schools to train at the same time and in promoting further school links. The schools, as a consequence, then trained their classroom assistants using staff from the schools and speech and language therapists.

9.39 There is growing demand from schools for access to training for staff in behavioural analysis. Four schools have undertaken training with the Institute for Applied Behavioural Analysis (IABA), which promotes non-aversive methods of dealing with challenging behaviour from pupils within school settings. These schools report promising results with pupils to date. Some ELBs have funded training with IABA.

Transition Stage Pupils

9.40 In SLD schools the transition stage begins at 14 years and continues until the pupil leaves school at 19 years of age. For young people with ASD this is a particularly traumatic time due to the changes which accompany leaving school and the preparations for this change. It is important that all professionals appreciate the extra care and attention that will be needed to help the young person with autism through the process to an appropriate provision or combination of provisions. A diagnosis of autism may be required in order to access autism-specific provisions. It is therefore important that older pupils have the opportunity for diagnosis if this was missed or unavailable when they were younger.

Models of Best Practice and Future Developments to be Considered

9.41 The following indicators of good practice were identified through the SLD survey (1998-2000) conducted by the Education and Training Inspectorate and through discussion with school principals:

- commitment and willingness of staff to meet more effectively the pupils' needs;
- staff knowledge of autism-specific issues;

- staff training in a variety of effective teaching and learning methods for ASD;
- an eclectic approach which recognises that some approaches work for some children and not for others and that some approaches are appropriate for some kinds of learning and not for others;
- recognition that pupils' needs vary from individual to individual, over time and for different areas of learning within individuals;
- positive staff relationships with pupils;
- appropriate educational plans drawing on assessment of each child's learning strengths and emerging skills which are individualised, and appropriately recorded;
- clearly defined and consistent use of effective methodology for encouraging independent work and peer-interaction;
- the use of a structured day;
- involvement of parents: support for, and partnerships with parents;
- enhanced links with outside agencies and professionals;
- support and teaching for pre-school children;
- provision for pupils in schools and nurseries from age 3;
- strong links with speech and language therapists;
- close liaison with post-school placement units.

9.42 Information obtained from school visits and liaison with the Department of Education and Science in the Republic of Ireland, and the Task Force on Autism (ROI), provides the following additional exemplars of developing practice:

- classes of no more than 6 pupils with one teacher and 2 classroom assistants;
- separate schools established for pupils with highly challenging behaviour with staffing ratio of 2 staff to one pupil;
- separate class for individual pupils with extreme challenging behaviour with one teacher and at least one special needs assistant;
- schools with their own full-time speech and language therapist;
- a school with its own occupational therapist;
- access to a variety of ASD professional development programmes;
- State funding of Birmingham autism course with access through local universities.

9.43 In other countries notable examples of good practice include the following:

- staff ratios determined according to individual need of pupil;
- speech and language therapists employed by school;
- whole-school training, initiatives eg Picture Exchange Communication System (PECS);
- access to specialist units for behaviour support;

- centres of expertise in autism for assessment, staff training and individual work with pupils with ASD in addition to their mainstream school placement.

9.44 The Task Group finds that provision for children with ASD and severe learning difficulties is improving and indicators of best practice are emerging which provide benchmarks for establishing effective provision. The findings indicated in this section are underpinned by two main elements:

- pupils with ASD and SLD need programmes which identify their individual needs, learning strengths and difficulties and provide guidance towards addressing the impact of the triad of impairments;
- there is a need for a policy guideline by ELBs for pupils with ASD and SLD in order to direct resources and promote multi-disciplinary initiatives.

9.45 Jordan (2001) identifies the main issues in providing an educational environment conducive to promoting effective provision for pupil with ASD. These are:

- structuring the teaching approach emphasising visual instruction;
- minimising verbal instruction to what is necessary;
- learning with and from peers as well as one-to-one support;
- therapeutic environments including sensory rooms and equipment.

9.46 In making recommendations the Task Group finds that provision must address the child's ASD and equally their SLD. The issue is in matching provision to individual needs (Jordan, 2001). The Task Group endorses current provision including separate classes and integration, though it is stressed that classes must be within a Key Stage and maintain opportunities for integration. The Task Group considers SLD schools are part of the continuum of ASD provision. Schools for SLD should audit their provision and prioritise the action they need to take to meet the challenges of increasing admissions of pupils with ASD and SLD. Provision to support children with ASD integrated into mainstream should also be developed. Schools for SLD should develop ASD outreach provision. A major finding of the Task Group is the need for staff development to ensure that teachers can individualise programmes to address each child’s:

- ❖ pastoral needs;
- ❖ communication needs;
- ❖ social and emotional needs;
- ❖ cognitive needs;
- ❖ long-term needs into adulthood.

CHAPTER 9

PROVISION FOR CHILDREN WITH ASD AND SEVERE LEARNING DIFFICULTIES

RECOMMENDATIONS

Recommendation 9(i)

The Task Group recommends that staff in SLD schools should have access to a range of training provision to meet their various needs and provided by the ELBs in co-operation with voluntary associations, the ASD support service and other training providers, for example, universities. This provision should include:

- whole-school training in ASD;
- training in a variety of teaching methods and approaches;
- training in behavioural techniques;
- access to conferences and workshops for ASD provided by agencies.

Recommendation 9(ii)

The Task Group recommends that SLD schools should have:

- a staffing ratio of one teacher and 2 classroom assistants to 6 pupils identified with an ASD; and additional staff to meet the needs of pupils experiencing severe challenging behaviour as indicated by multi-disciplinary assessment;
- appropriate accommodation to meet pupils' needs;

- sufficient additional equipment to meet the needs of pupils with ASD;
- speech and language therapists appointed to their staff;
- access to occupational therapy with ASD specialist knowledge;
- access to music therapy;
- adequate funding to run ASD-specific summer schemes.

Recommendation 9(iii)

The Task Group recommends that SLD schools should maintain:

- home-school ASD programmes which encourage the full involvement of parents;
- partnership links with voluntary associations in order to avail of their services and support.

CHAPTER 10

PROVISION FOR CHILDREN WITH ASD AND CHALLENGING BEHAVIOURS

This chapter reviews the current provision for children and young people with ASD who have behavioural difficulties associated with their condition, the school settings and/or the circumstances of their placement, or have a specifically diagnosed behavioural disorder. A number of recommendations are made to inform current practice and to effect improvement.

Introduction

10.1 In many instances, teachers and parents regard the issue of ASD as less problematic than the issue of challenging behaviour. Teachers and parents express concern and anxiety about the difficulties posed by a range of issues, including aggressive outbursts, self-injurious behaviour, and bullying of this group of children and young people. There is evidence of increasing suspensions and expulsions from schools among pupils with ASD, and it is well documented that families with a child with an ASD are more likely to experience high levels of stress and anxiety. (Fitzgerald and Matthews, 2000). There is also evidence that the current provision does not serve well the needs of a small minority of children who, as a result, are placed in schools outside Northern Ireland or find themselves temporarily in psychiatric hospitals.

10.2 The most difficult aspect of challenging behaviour is the apparent unpredictability of the behaviour; what may be considered challenging at one time, may not be at another, and what may be regarded as a trigger to challenging behaviour on one occasion may not be in another circumstance. In addition, the recognition of what constitutes challenging behaviour varies across the schools and across the age range.

10.3 This chapter will explore briefly the nature of the challenging behaviour alongside the impact of the pupil's ASD, his/her environment and the approaches used to motivate and respond to the pupil's reactions in confrontational situations.

10.4 As part of the work of the Task Group, questionnaires were send to 22 special schools for children with severe learning difficulties. Between 20% and 26% of children in these schools have ASD. Interviews were also held with a number of principals, teachers, ASD advisors and parents in order to identify the problems surrounding challenging behaviours and the support provided to deal with the issue. The questionnaire indicated that there were some 64 pupils regarded as exhibiting very challenging behaviours across the special schools and, whilst a range of support mechanisms were in place, the outcomes were variable and largely unsuccessful. In the mainstream situation, schools were more likely than their special school counterparts to suspend or expel a child with challenging behaviours. In a minority of instances, effective intervention helped a child to remain in school, to access purposefully the curriculum of his peers and to develop appropriate social skills to secure relationships with peers and adults. It is worth noting that the problem of challenging behaviours is confined to a very small number of children and that current provision has not yet produced satisfactory arrangements to guide intervention in this area.

Challenging Behaviours

10.5 Children with ASD rarely exhibit aggressive behaviour and, when they do, it is frequently as a result of their inability to respond appropriately to situations which are challenging to them and often frightening or frustrating. Knowledge of autism informs us that children with the condition do not develop relationships easily and do not share a sense of trust and expectancy of support with adults close to them. Children with ASD rely on a sense of security which derives from their familiarity with routines and uniformity. Change in routines or the environment affect the children's well-being and, on occasion, anger is a consequence. What is clear is that the behaviour has an explanation, and the trigger to the behaviour may be something quite innocuous or trivial to others but of significant importance to the child.

Much of the literature defines challenging behaviour as a problem of such severity and regularity that it results in significant dissonance between the needs of the individual and the human and physical environment. Emerson et al (1987) put it thus:

> ***"behaviour of such intensity, frequency or duration that the physical safety of the person or others is placed in serious jeopardy or behaviour which is likely to seriously limit or deny access to the use of ordinary facilities. Ordinarily, we would expect the person to have shown the pattern that presents such a challenge to services for a considerable period of time. Severely challenging behaviour is not a transient phenomenon".***

Some pupils with ASD present as being very passive learners. This can be regarded as challenging to some parents and teachers. The needs of these pupils should not be disregarded within the classroom simply because they do not cause disruption. Many teachers find that the needs of passive learners can be effectively addressed through structured teaching and by identifying the pupil's motivation needs.

10.6 The evidence from the literature indicates the need to analyse the situation in which the challenging behaviour occurs as an integral aspect of addressing the challenging behaviour (Jordan, 2001).

10.7 Aston (2001) highlights the issue of fear as having different qualities in children with ASD. Aston suggests that fear is more pervasive among children with Asperger syndrome, and can arise from everyday stimuli, which leave the child distraught. The difficulties are not confined to any age group and tend to remain over time and express themselves in different but clearly related situations. Aston mentions additional problems: for example, the difficulties in sexual relationships that both men and women with Asperger syndrome may experience. Klin and Volkmar (2000) also refer to the fact that children with Asperger syndrome are at a greater risk of developing depression and emotional difficulties. There is, therefore, the need to distinguish among the varieties of behaviours which are considered challenging or violent (Ashdown, 1993). Thus the concept of challenging behaviour is complex.

10.8 The factors influencing behaviours are:

- psychological;
- physical;
- communication-related;
- situational;
- environmental.

10.9 A child with an ASD may exhibit different or unusual behaviour because of an illness or discomfort, or a new and unfamiliar occurrence or meeting unfamiliar persons, which interrupt the routine of events the child relies on. Challenging behaviour may also occur because the child is unable to express his/her feelings or to communicate needs, and may do so by running away, expressing fear, withdrawing or being destructive or aggressive. In every situation the behaviour has an explanation. **The challenge to parents and teachers is to find the explanation for the behaviour and either teach the child how to cope, or manipulate the environment or the circumstances to ensure that the child settles and interacts positively.**

10.10 Most parents and teachers recognise challenging behaviours and many of the submissions to the Task Group detailed behaviours that were considered particularly challenging. In mainstream schools, most of the challenging behaviours were verbal or confrontational, and included examples such as running from class, refusing to do work, or disrupting lessons. Situations may be compounded by mutual misinterpretations. In the special school setting, the challenging behaviours were identified as being more aggressive and, on occasion, violent and uncontrollable. One principal expressed concern about older and physically stronger children with challenging behaviour. Another principal wrote that children with severe challenging behaviours were more difficult to teach in mixed ability settings. Several principals noted the rise in the ASD population in their schools, which created greater challenges for the school, particularly in the deployment of staff and resources. A number of responses indicated that the issue raised health and safety concerns and that other children had to be protected as a priority. One principal requested consideration of more specialist provision as a priority and as a means of preparing a child for reintegration. The principals expressed strong support for the need to review provision for this group of children and they indicated the need for more in-depth and relevant training and a broader continuum of provision.

10.11 In terms of provision, the schools employed a variety of strategies and approaches: most received support from the ELBs and from health and social services. External support included additional classroom assistants, access to training and advice and assistance from ASD advisers, outreach teachers from the special schools, clinical and educational psychologists, and from child psychiatry and voluntary groups. In most responses, the special school principals considered that the school could provide adequately for the needs of children with challenging behaviours but they felt that they were finding it increasingly difficult to cope with children with very severe challenging behaviours. In one ELB, the SLD schools had access to a designated challenging behaviour team comprising a teacher, classroom assistants, clinical and educational psychologist and a behaviour nurse therapist. This last was regarded as invaluable to the success of intervention provision. For their part, the principals in mainstream schools often judged that mainstream placement was inappropriate.

10.12 In discussion with some of the principals, it became clear that there was inadequate assessment of individual children's needs and, in particular, little baseline information on the impact of the environment on the child's ability to settle and respond. In addition, less than adequate attention was placed on promoting the child's communication skills as an integral aspect contributing to the challenging behaviours. What emerged from the findings is a picture of schools trying constantly to deal with the challenging behaviours using general strategies, which often failed. In some schools, manipulating the physical environment, employing a high staff:pupil ratio, and following a strict structured approach based on the principles of TEACCH did have good effect on the social outcomes for the child. In 4 schools, staff had had or were receiving training from the Institute of Applied Behavioural Analysis; they reported success in establishing procedures to address challenging behaviours. In one school, for example, which has adopted the approach at a whole-school level, a number of useful principles have emerged which provide a useful model to others. These elements include:

- intensive training in behavioural analysis for a number of key staff;
- whole-school awareness, and commitment to the implementation of the approach;
- clear leadership and direction from the principal;
- comprehensive individual assessment and intervention planning;
- home-school partnership;
- an emphasis on a diverse use of strategies matched to individual needs;
- ongoing support from external agencies to help promote monitoring and evaluating.

10.13 In general, there is little confidence or indeed agreement among teachers as to what can be done when severe challenging behaviours arise. In addition, it is important to note that much initial behaviour regarded as challenging is often replaced by additional learned and inappropriate behaviours, which in some instances can become obsessional over time. Comprehensive assessment is required to clarify the essential behavioural circumstances which cause problems for the child. It is known that a key feature of ASD is an inability to develop appropriate social interaction skills and knowledge. Much of the literature indicates that children with challenging behaviours rarely have control over their environment and with effective support can cope with or extinguish unnecessary habits or behaviours (Keogal et al, 1997; Donnellan et al, 1988).

10.14 It is the findings of the Task Group that those who work with children with ASD need to have a sound knowledge of the nature of autism and of the influence of the autism upon the individual child. It is further clear that a detailed knowledge of a child's learning strengths and weaknesses, including an analysis of behaviour, is crucial to planning intervention.

Intervention: Promoting Best Practice

10.15 Planning to provide an effective environment conducive to learning should be underpinned by two main themes:

- a whole-school approach and ethos, promoting positive behaviours and socialisation;
- an individually developed programme of intervention to address the child's needs and providing opportunities to work alongside peers in an appropriate and jointly beneficial manner.

10.16 It is suggested that provision should include:

- training for all staff, particularly for key workers;
- sufficient staffing and resources;
- effective arrangements for assessment, monitoring and evaluation of progress.

10.17 Dealing with the issue of challenging behaviour begins with an acknowledgement of the problem and an intention to address the behavioural difficulty. In all instances, this will entail a collation of information about a breadth of areas, including the individual profile of the child, the circumstances of the challenging behaviours, the members of staff involved and the teaching approach and curriculum content in use when difficulties arise. In other words, there is a need to assess the global aspects of a child's situation and it is important to accept that the child's challenging behaviours may result from conditions outside the child's control and not solely as a result of an ASD. Whole-school procedures must be established and clearly understood by all. Prevention is a major consideration and it is crucial that schools develop an ASD-friendly approach linked to and integrated with the pastoral and special needs system of the school. Good standards and behaviours emanate from recognisable rules and procedures.

10.18 The Task Group finds in the best practices that staff confidence is strongly associated with appropriate training and whole-school commitment to effective provision. In such circumstances, schools develop a range of strategies and procedures for improving behaviour within the school and the classroom context.

10.19 There has been significant interest in the field of challenging behaviour in the past 10 years and it is evident that teachers and parents need access to a breadth of knowledge about the subject and to a system of support, advice and training. The main approaches used to manage problem behaviours include biological, social, educational and psychological. It is without doubt necessary to explore pharmacological interventions, which have been the staple intervention of the psychiatric services. While there is some debate about medical interventions, it is clear that some children respond to medications. Children with ASD, like other children, may have additional impairments such as a hearing or visual difficulty or epilepsy which require attention. A medical examination is often recommended as an initial action if only to rule out physical causes. Social intervention strategies focus on creating environments which reflect the child's ASD condition and which provide a sense of security for the child. The aim of educational intervention is to increase the individual's skill and experiences to assist progress; the psychological approaches provide focus on the behavioural, psychodynamic and cognitive perspectives. While mention is noted in this chapter and throughout the report of differing methodologies, readers are referred to the literature for more in-depth information (Jordan, 2001; Lovett, 2001; Harris and Weiss, 1998; Aston, 2001).

10.20 Teaching appropriate functional behaviours and providing support for a child at times of challenging behaviours are characteristic of positive behavioural programming. This approach identifies or analyses the function of the behaviour as a means of communication. The results which emerge direct the creation of preventative strategies, and indicate environmental and instructional adaptations which may help the individual to cope. The challenging behaviour must be clearly identified in order to ensure that it can be controlled or eliminated. Exponents of behavioural analysis strongly promote the need to observe the child during assessment and to identify the problem behaviour, when it occurs, how often it occurs and in what settings or circumstances. The information is vital to planning intervention and is often written into an 'ABC' action plan: A being the antecedents of the behaviour, B, the behaviour itself and C, the consequence. Zarkowska and Clements (1996) describe a more intricate model of intervention, which is described in detail in Jordan (2001). La Vigna details an ABA approach, which focuses on analysing the behaviour in terms of its causes and consequences for the child within a reinforcement survey.

10.21 The Task Group finds that, following comprehensive assessment by a variety of professionals, intervention should be individually developed and should include a range of resources and settings to match need to provision.

10.22 Research findings indicate that the use of strategies which combine behavioural methods and counselling techniques helps foster social interaction and reduce challenging behaviours (Howlin and Rutter, 1991). Indeed the humanistic approach as described by Nind and Hewitt (1994) is regarded as a useful approach for children with ASD, although its use is rare across the schools. The Task Group considers that schools should review and make use of interventions that develop from a whole-school approach which reflects autism strategies, and promotes teaching and learning based on individual planning. The following interventions should be available in schools and appropriate use made of those which address effectively individual needs; the interventions include:

- play strategies to foster turn-taking and social skills with younger children;
- intensive interaction to encourage communication and to help eliminate inappropriate behaviours;
- intrusive teaching which encourages children actively to seek help and to be engaged in class activities;

- stress-reducing activities to help individual children to cope with difficult situations, including managing anger and aggression;
- peer training to help others develop an interest and empathy for children with ASD;
- friendship and buddying techniques, eg Circle of Friends, to help children with ASD to develop their social skills and to make and maintain friendships;
- integration opportunities to allow the children with ASD and their peers to work alongside one another in various settings.

10.23 Much has been written to indicate that aversive approaches, and approaches which include aversives, to manage behaviour focus heavily on specific behaviours rather than on the diagnostic components of autism as described within the triad of impairments. It is the findings of the Task Group that modifying unacceptable behaviours through intervention strategies must be carried out non-aversively and in line with the DE Circular 1999/10 ensuring the pastoral care and child protection of the child.

Range of Options for Challenging Behaviours

10.24 A range of differentiated provision is crucial to meeting the needs of children with ASD and challenging behaviours. This report favours support in the least restricted environment which, in the majority of instances, will be the child's mainstream school; for some children, appropriate placement may mean alternative provision, at least for some time, in a specialist setting or class. For the minority of children whose behaviour is severely challenging, alternative placement may need to be developed to provide time for comprehensive multi-disciplinary assessment, individual guidance and staff training as a preparation for reintegration. In the latter case, the Task Group suggests that a more creative approach is necessary to ensure that the withdrawal programme targets the child, his/her parents and the staff who will remain responsible for his/her provision on re-entry to school. Such alternative provision will require expert involvement and outreach flexibility to secure effective progress.

10.25 In general, there is the need to ensure that schools have access to multi-disciplinary support, and to an analysis of the ecology of the classroom in order to consider the variables of organisation, classroom layout, seating arrangements, routines, and pupil and teacher mobility (Thomas, 1992). Additional classroom factors including the noise level, transitions, interruptions, staff and routine changes and unclear requests and teacher instructions and teaching styles must be observed and analysed to establish a baseline position for effective provision.

CHAPTER 10

PROVISION FOR CHILDREN WITH ASD AND CHALLENGING BEHAVIOURS

RECOMMENDATIONS

Recommendation 10(i)

The Task Group recommends that a range of differentiated provision, including resources, should be made available to meet the needs of children with ASD and challenging behaviours, and should be sufficiently flexible to allow the child to avail, where recommended, of different placements, including specialist and residential provision. The range of provision should include:

- an ASD/challenging behaviour referral unit for pupils unable to integrate fully into their school and situated to serve the needs of a geographical sector of schools;
- residential provision, short- and long-term, with an emphasis on reintegration.

Recommendation 10(ii)

Training in identifying and managing children with ASD and challenging behaviours should be provided for parents, teachers and classroom assistants.

Recommendation 10(iii)

Multi-agency and multi-disciplinary support and comprehensive assessment of the child and of the ecology of the classroom should be available to all schools experiencing challenging behaviours to assist staff in the creation of a positive environment and the implementation of effective programmes.

Recommendation 10(iv)

Research should be funded to clarify the complex needs of this population, and identify the types of resources and approaches which are most effective.

Recommendation 10(v)

The Departments of Education and Health, Social Services and Public Safety should seek to establish protocols and guidance on collaborative working at ELB and Trust level.

CHAPTER 11

FURTHER AND HIGHER EDUCATION, TRAINING AND EMPLOYMENT

This chapter describes the common issues arising in Further and Higher Education, training and employment for people with ASD. Recommendations are given for the development of services in these areas.

INTRODUCTION

11.1 The information on incidence rates in primary schools indicates that there have been large increases in the numbers with ASD recently (see Chapter 4). These increases are not evident as yet in the Further and Higher Education, training and employment sectors where the numbers remain relatively low. Practitioners in the field, however, report that numbers are starting to increase and the indications are that more people with ASD will be seeking services in these areas.

11.2 A number of research studies have commented on provision and outcomes in this area. A recent research survey carried out by the National Autistic Society, "Ignored or Ineligible" (Burkin et al, 2001), highlights the position of adults with ASD. This indicates that less than 6% of adults with ASD are in full-time employment, the figure falling to 2% for those at the less able end of the Autistic Spectrum. The parents who were interviewed on this study stated that many of the serious problems appeared in the transition between school and adult life:

> ***"But most of all this survey throws into sharp relief the lonely, lengthy and confusing battle for services which faces people with autism and Asperger syndrome, and their carers, at the transition from childhood to adulthood. The Government Policy of inclusion within the education system is raising expectations, which are***

> ***only shattered in adulthood as current provision is woefully inadequate. The crucial years of transition can make the difference between an unhappy and dependent existence in adulthood or a more independent and fulfilled life" (Burkin et al, 2001).***

11.3 Until relatively recently there have been very limited Further Educational opportunities of any kind for individuals with ASD (Howlin, 1997). Group studies (Tantam, 1991) indicated that only 2 out of 46 had received Further Education and Newsom et al (1982) identified 11% receiving Further Education. A lack of knowledge combined with poor diagnosis often resulted in an inability to provide the right learning environment or support for individuals with ASD. With appropriate educational provision, progress can be made and Howlin and Goode (1998) have noted improvements between 1960 and 2000 with less institutional care and increased employment opportunities. Kunce and Mesibov (1998) emphasize the importance of appropriately-structured educational programmes in the achievement of academic and occupational attainments. Asperger (1944) comments on the variable outcomes of his patients but gives examples of many who excelled in later life including a professor of astronomy, mathematicians, ethnologists and chemists and suggested that perhaps "only such people are capable of certain achievements. Their unswerving determination … their narrowness and single mindedness … can be immensely valuable and lead to outstanding achievements in their chosen areas." (translation by Frith, 1991).

11.4 The Department for Employment and Learning (DEL) are committed to improving access to Higher and Further Education. At the launch of a Register of Support Workers for Students with Learning Disabilities (Jan 2001) the then Minister, Dr Seán Farren, said:

> ***"At the recent launch of Adult Learners Week, I drew attention to the Programme for Government which states that the Executive will seek to provide high quality education for all with equal access for all. This is important for social and community development and is a major engine in our economic development to which people with learning difficulties have much to contribute.***

> ***"My Department is committed to promoting participation in learning. In Higher and Further Education, action has already been taken on a number of fronts, both legislative and non-legislative, to improve the rights of, and access by, students with learning difficulties and/or disabilities".***

PREVALENCE RATES AND PROJECTIONS

11.5 DEL records information on students with disabilities which is provided by the Universities and Colleges of Further Education. This is collected by Agencies such as the Higher Education Statistics Agency and passed to the Department. Information on a small number of specific categories of disability is recorded, eg Dyslexia and Deafness, but ASD is not one of the listed disabilities. The remaining disabilities are recorded under broad disability categories.

Further Education

11.6 The Careers Officers in DEL have 70 people with ASD on their caseload, 54 from the special school sector and 16 from mainstream schools. It is estimated that about 20 of these progress to Further Education. Those from the special school sector would mainly be on Jobskills Access courses and those from mainstream schools on Jobskills, general academic, and vocational courses. The Learning Support Co-ordinators in the Colleges reported that the maximum any college had was 2 people with ASD and some colleges had none. It was thought that numbers with ASD were increasing slowly at present and future increases were anticipated.

Higher Education

11.7 Five people with ASD were identified by the Disability Officers as currently attending the 2 local Universities. They indicated that these figures represented those that had a definite diagnosis and true figures of those with ASD may be much higher. The Disability Officers also felt that improved support mechanisms, and the fact that people were successfully completing courses, would encourage others, resulting in increased participation in Higher Education.

Employment Training

11.8 Specific training for people with ASD is not available but it is estimated 20 students are trained under the Jobskills and Jobskills Access Courses provided by Training Organisations and vocational courses provided by voluntary organizations.

Employment

11.9 The Disablement Employment Advisors (DEAs) of the Training and Employment Agency have currently 6 people with ASD on their caseloads. They have also placed 5 people into employment in the last year. Numbers have increased recently and are expected to increase further.

RANGE OF PROVISION

11.10 A number of studies have emphasized the importance of the quality and range of provision if a positive outcome is to be achieved for young people moving from school to college, work and independent living (Lord and Venter, 1992, Howlin, 2000). Other studies have shown that the right provision can make a difference, helping to minimise or avoid secondary behaviour or emotional problems, and can ensure that the individual young person develops his/her existing skills to the full (Jordan, 1995, 1999).

11.11 Submissions to the Task Group by students and parents indicate a range of experiences, some negative and some positive. The parent of one student with an ASD, who achieved an NVQ Level 2 in Business Administration, stated ***"She only achieved this because one special wonderful tutor took a personal interest and recognized her difficulties because he had a son with autism".*** Her experience at college had been poor as she was shunned by her peer group as being "different" and found difficulty coping with unstructured time such as lunchtimes. One of the tutors tended to shout at her and this lowered her self-esteem. Another student had mixed experiences of employment training. An initial course in computing was found to be "stressful" although they gave every consideration to his needs. The environment was too confined and too disorganized for him to feel "comfortable". He then moved to do an NVQ Level 2 in Warehousing and has since got a job as a storeman. His experience is summed up as follows: ***"they took on board what his needs were, found a suitable placement and delivered a good social skills programme. They visited his placement regularly, and developed social and work skills through group work, sport/leisure activities and outdoor pursuits".***

11.12 A student with Asperger syndrome studying for a degree initially had problems with methods of study and examination stress but stated that ***"support from student support services, course advisers and lecturers was excellent".*** Another parent commented that ***"there should be resources provided for cross-cutting activities between education and training for employment".*** Lynne Moxon, an Educational Psychologist with many years' experience of ASD, works in a Residential Further Education College for Autism in Sunderland and shared her experience with the Task Group. She made a number of suggestions regarding best practice in the organization of Further and Higher Education for people with ASD:

- there must be consistency of contact from support workers, and continuity in staffing of key workers is important;
- service provision must be individualized, taking into account knowledge of needs, wants, skills, behaviours and anxieties;
- staff must be well trained in the nature of ASD. The right to self-determination and risk-taking and the ability to achieve these aims depends on well-trained, knowledgeable and experienced staff;
- new opportunities must be made available, but from a familiar and secure environment. Changes must be introduced and planned in a systematic way;
- meaningful activities are needed to prevent regression to stereotyped, repetitive routines and other self-stimulating activities;

- to provide support to colleges, it is important to develop an experienced specialized group to plan and monitor provision, and to deliver staff awareness and training to a broad range of staff;
- a suitable environment is very important for people with ASD;
- consideration must be given to unstructured time such as breaks, lunchtimes, as this is often a difficult area;
- learning styles must be considered and accommodated.

Further Education

11.13 There are no courses designed specifically for students with ASD but in theory all courses are open to them if they fulfil the entry requirements. Many students with ASD are on the Jobskills Access courses which have been designed for those with special educational needs and which last for 3 years. (Additional funding is provided to support students). These courses concentrate on pre-vocational skills, personal development and vocational training, leading to a National Vocational Qualification at Level 1 or a National Skills Profile. Classes tend to be smaller and more student support is available. They adopt a client-centred approach focusing on individual needs. On these courses there is more stability and routine which suits those with ASD. Students stay together and are generally in the same classroom most of the time. They also build up self-supporting relationships and socialize together.

11.14 Work placements are organized, and supported by training support staff from Disability Action. Their caseload of around 70 covering all disabilities means that support has to be prioritised according to need with some people being visited once a week and others once every 6 months. One-to-one support is only available for a maximum of one day if necessary. Their role is to liaise with students and employers, provide disability awareness and deal with any problems which arise in the placement.

The support staff report that success in work placements is highly dependent on a good match between the student and the appropriate work tasks and environment. Staff and co-workers must be aware of the disability and individual needs.

11.15 The general courses in the colleges offering Jobskills, vocational and academic courses are open to those with higher functioning autism and Asperger syndrome. These courses would consist predominately of non-disabled students and be less stable in terms of changing classroom environments, and changes in staff and students. There is generally less routine with frequent changes and more need for independent decision-making and time management. Some students with ASD have been very successful on these courses, going on to obtain employment, but the lack of routine and limited support can cause problems. The Careers Service and 'Skill', the National Bureau for Students with Disabilities, report that ASD students find it difficult to cope with the lack of routine and the independence that is required in college. They often displayed aggressive or disruptive behaviour which the teachers found difficulty coping with. They had problems relating to the other students and bullying and scapegoating were problems for some. Structuring free time and travelling to and from college also presented problems.

11.16 Each college has a Learning Support Co-ordinator with the responsibility to support all students with disability. DEL provides additional funding for students with a disability who have a learning difficulty. An additional support fund of £310,000 is also provided to cover the 17 colleges' support needs. One Learning Support Co-ordinator stated that the funding structure based on colleges was suitable for most disabilities, but for ASD students much more intensive one-to-one support was often necessary, involving higher costs, therefore an individual funding package would be more suitable.

11.17 In terms of support the Careers Service in DEL work with the schools and colleges on transition planning, advising on suitable courses and the support and adjustments that may be necessary. 'Skill' offers additional support to parents, students and colleges in areas such as funding, policy, adjustments and disability awareness. There are currently 25 Special Needs Careers Officers working in the special school sector and 100 Careers Officers working in the mainstream sector. They are based in Training and Employment Agency offices throughout Northern Ireland.

Higher Education

11.18 Students with ASD who have higher functioning autism or Asperger syndrome can often be very successful in Higher Education. High intellectual ability, high ability in specific areas, obsessive interest in particular areas, a liking for routine and rules and a willingness to perform repetitive tasks could all be positive factors in academic success.

11.19 When students apply to University they are asked to state on the University Central Admissions System form if they have a disability and if they have any special needs. Each University has a Disability Officer to support students with disabilities, who would then liaise with the student and staff in the University to develop support structures and provide disability awareness. The Careers Officers and ‘Skill’ also offer advice during this transition period.

11.20 Numbers in Higher Education reported by the Disability Officers are 4 at primary degree level and one progressing to doctorate study. Problems presented include difficulties communicating, relating and integrating with other students, inability to travel or access facilities in the University independently, difficulty taking notes, problems with standard examination procedures, a lack of knowledge/understanding from students/lecturers and behaviour problems in University accommodation.

11.21 In terms of funding, students with ASD would receive a Disabled Students Allowance which can be used to support their academic needs related to their disability. This can be used to fund a support worker. A good example is one student at Queen’s University who receives 25 hours per week support while travelling and on the campus. The support worker also takes notes at lectures as the student has co-ordination problems, takes photocopies and helps him access the library facilities. The Universities are also paid a “widening access premium” for each student who is in receipt of the Disabled Students Allowance.

Training and Employment

11.22 A range of Training and Employment Programmes are provided by DEL to meet the needs of people with disabilities. These programmes are not designed specifically for people with ASD but can meet their needs in many instances.

Jobskills Access

11.23 The Jobskills Access courses as provided in Further Education Colleges are also provided by Recognized Training Organizations. Extra funding is provided to give additional support related to the individual's disability. DEL also fund Disability Action to provide support for trainees with disabilities on these courses.

Access to Work Programme

11.24 This provides assistance with Aids to Employment, eg specialized computers, desks, wheelchairs etc, travel to work, care assistance, support worker or communication support.

Job Introduction Scheme

11.25 This provides the opportunity to try a job for a period of up to 13 weeks before the individual or the employer decides it is suitable. It has been used in the past for trainees with ASD to check if the job tasks, environment and working conditions are suitable or to see if the job could be re-designed to make it more suitable.

Employment Support

11.26 This scheme provides financial support to employers to compensate for the effects of the person's disability on their productivity. A number of people with autism are employed under this scheme. In most cases it has been used to restrict the range of tasks the individual needs to cover (mainly in the inter-personal/ communication areas) and to keep work routines and environments stable.

New Deal for Disabled People (NDDP)

11.27 DEL and the Social Services Agency are jointly responsible for NDDP. Individuals accessing NDDP will be guided by a Personal Adviser towards appropriate NDDP options, including External Gateway (eg refresher and foundation skills training), Pre-employment Training and Jobskills. They will receive assistance in their jobsearch activity and once in employment can continue to receive DEA support from their Personal Advisor/Disablement Employment Advisor, if this is required. Disablement Employment Advisors are based in Training and Employment Agency offices throughout Northern Ireland.

Jobskills

11.28 Jobskills encompasses 3 distinct, but interrelated, strands of training, ie Access, Traineeships and Modern Apprenticeships (MA): Access training has been referred to earlier. Jobskills Traineeship and MA programmes are provided through Training Organisations (TOs). TOs manage, monitor and review the process of training. They draw up Individual Training Plans that meet the Key Skills required by DEL and the training objective in the Training Credit, and place and support trainees in vocationally appropriate training/employment placements.

Supported Employment

11.29 The Supported Employment Model was developed in the 1970s through the pioneering work of Gold (1980) and Bellamy (1979) in the United States. Their work demonstrated that people with significant intellectual and behavioural challenges were able to complete complex vocational tasks given the appropriate instructions and support. From this work a new model was developed where people with disabilities were placed in integrated employment settings and assisted by a job coach or support worker to do a job. A number of voluntary agencies in Northern Ireland are operating this model successfully and some people with ASD have been placed in employment through it. The Northern Ireland Union of Supported Employment co-ordinates work in this area and can supply information on individual agencies.

VIEWS OF SUPPORT WORKERS

11.30 The views of the support workers on the training and employment of people with ASD emphasize the importance of the person/job match, maintaining routines and educating employers and peers on the behaviour and needs of people with ASD. Examples are given of success, such as the following: ***"His work on retrieving and downloading information on computer is of an exceptionally high standard. It is very repetitive in nature and previously there have been difficulties maintaining staff in the post because of this".***

11.31 For another employee with ASD the job had to be redesigned so that he did not have to use the phone, deal with the public or interact with other departments. His performance in an administration post is now of a high standard and very reliable. One of the remaining problems is that he does not want to take holidays.

STAFF TRAINING

11.32 As described in Chapter 2, ASD is a complex disability with wide variation in the levels of intellectual ability, communication skills, social skills and behaviour problems. People with ASD also vary in the learning styles that suit them best and in their sensitivity to stress and environmental stimuli. Where specialized training/education is required, it should be delivered in an environment where the social, communication and education needs can be accurately identified and addressed (Howlin, 1997). Given the complexity and variation in the disability all staff working with people with ASD should be well trained.

11.33 Most of the people working in the Higher and Further Education, training and employment sectors have come across very small numbers of people with ASD and have not had the opportunity to build up a lot of experience of working with them. None of the support staff, Lecturers, Careers Officers, Disability Officers or Disablement Employment Advisors are specialists in ASD but have a more general role working with all disability groups. Training regarding working with ASD is not formalized and in many cases it is minimal or limited to background literature. There are some good examples of training undertaken but this has generally been organized by individuals who have an interest in the subject. All the training courses have been in England. Two staff from the Careers Service received training from Gerald Lombard of Independent Psychology Services in Wiltshire, and were very impressed by the standard and usefulness of the course. Their intention is to bring this training over for the rest of the Careers Service. In another case a Learning Support Co-ordinator received training by Think FE in Manchester regarding Asperger syndrome. When he returned he set up training for the staff at the college.

FUTURE TRAINING NEEDS

11.34 All practitioners who were consulted in the Further and Higher Education, training and employment sectors expressed a desire for further training and information regarding ASD. They were aware of the complexities in the area and felt that they would be more confident if they had more knowledge and experience of dealing with this group.

11.35 Some also stated that in working in such a specialized area they often felt isolated and would appreciate an opportunity to share their experiences with others working in the field or to consult “experts” for advice and guidance.

MODELS OF GOOD PRACTICE

Further Education

11.36 European Services for People with Autism (ESPA) run a specialized residential Further Education College in Sunderland for 150 people with ASD. It takes referrals from all over Britain and provides a 24-hour curriculum over 43 weeks. They have a multi-disciplinary staff including teachers, psychologists, speech therapist, consultant psychiatrist, occupational therapist and support workers. Most students attend one of the local FE colleges for part of the course where they receive support. This is given in a number of ways: they can contact staff by phone if there is a problem; help is given to develop relationships with mainstream tutors and peers; support is given to cope with unstructured time at mealtimes and breaktimes; tutors are given background support and advice when required; help is given with assignments, study skills and management of workload; a risk assessment is completed for each individual. The tutors in the local FE Colleges have access to a consultancy team in the Residential College to discuss problems and develop solutions. At the College they pay a lot of attention to non-academic skills and feel it is important to improve and develop social and inter-personal skills. Behaviour self-management skills are taught and also independent living skills such as shopping, transport training etc. The College is funded by the Department for Education and Skills for 38 weeks, with the Department of Health funding an additional 5 weeks to cover an extended college term of 43 weeks.

Employment

11.37 Prospects Employment Consultancy based in London is run by the National Autistic Society and works only with people with ASD. They run a Supported Employment Scheme funded by the Department for Education and Skills and staffed by trained and experienced consultants working specifically with ASD. Support is provided at two levels: employment consultants work alongside the individual to enable them to carry out their role and responsibilities fully and to ensure their successful integration into the corporate culture. During the early stages of employment, guidance is given on issues such as establishing a routine and planning for changes. Equally important is the advice and support given to the individual’s colleagues in the work environment - employment consultants can advise on how best to structure the applicant’s workload and enable colleagues to be direct in their communications to the applicant. It has been very successful in obtaining and maintaining jobs for people with ASD.

Higher and Further Education

11.38 Prospects Employment Consultancy also run a student support service for people with ASD. Advice and information is given by employment consultants in helping to develop an understanding of the difficulties people with Asperger syndrome may face with regards to their studies. They also work on a one-to-one basis with the student and liaise with staff and peers. Help is also given in setting up support networks such as mentors and providing effective strategies to aid independent learning.

NORTH-SOUTH OPPORTUNITIES

Employment

11.39 The STAAR project (Structured Training for Adults with Autism in Roscommon), a partnership between St Michael's School and the Brothers of Charity, has successfully developed a supported employment project to develop employment opportunities for school leavers with ASD using the TEACCH approach. This has now been mainstreamed with funding from the Health Board. It would be useful for supported employment projects in Northern Ireland to have the opportunity to consider this employment scheme jointly with their counterparts in the Republic of Ireland and to establish links which could help the future development of comparable services for adults with ASD.

CHAPTER 11

FURTHER AND HIGHER EDUCATION, TRAINING AND EMPLOYMENT

RECOMMENDATIONS

Recommendation 11(i)

Training

All staff working with people with ASD should be well trained within a co-ordinated training framework which makes use of the expertise in the education sector and includes the key agencies and the voluntary sector.

Recommendation 11(ii)

Expert Group

A Reference Group of Professionals should be established, representing the various agencies and the voluntary sector, who would advise and support on ASD issues.

Recommendation 11(iii)

Multi-Disciplinary Approach

People with ASD should have access to a multi-disciplinary service to assist their post-school placement. This may include psychiatrists, social workers, speech therapists, occupational therapists and psychologists.

Recommendation 11(iv)

Late Diagnosis

Diagnostic services for young people and adults should be improved in order to reduce the number of young people and adults with ASD who do not have a diagnosis.

Recommendation 11(v)

Support Service

A support service, to include access to a residential facility where necessary, should be established, for individuals with higher functioning autism or Asperger syndrome to ensure their successful completion of Further and Higher Education.

Recommendation 11(vi)

Funding for Further Education

Individual funding packages should be provided for students with ASD to ensure that colleges can effectively provide for their education.

Recommendation 11(vii)

Statistical Information

DEL should develop a database to identify numbers in Further and Higher Education, training and employment. This information should inform the future planning of services.

Recommendation 11(viii)

Training/Employment Support

In order to build up experience and expertise of supporting people in employment, a specialist approach needs to be adopted. A number of support workers should specialize in order to build up expertise in working with people with ASD, a number sufficient to ensure that all people with ASD can have access to an appropriate level of support.

Recommendation 11(ix)

North-South Opportunities

Exchange visits, seminars, and conferences should be set up to bring people together, establish networks and generally give more support to people working in this area.

Recommendation 11(x)

Transition Planning

The Transition Planning process should be improved in order to ensure the effective involvement of all relevant professionals and parents. Apart from educational provision it should address the areas of social and life skills, behaviour, environmental needs, risk assessment and support needs. A profile of information gathered throughout their school life should follow the pupil to any new provision.

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- Down
- Dungannon and Armagh
- Newry and Mourne
- North Down and Ards
- Omagh

PAPA Families

PAPA Asperger Group

Parents and Families

Parents of Children with ASD, Consultation through PAPA

Mrs Liz Aiken (Chairperson, PAPA)

PEAT (Parents’ Education as Autism Therapists)

Skill, Alison Anderson

GLOSSARY

ABA	Applied Behavioural Analysis
ADHD	Attention Deficit with Hyperactivity Disorder
ASD	Autistic Spectrum Disorder(s)
BELB	Belfast Education and Library Board
CARS	Childhood Autism Rating Scale
CASS	Curriculum Advisory and Support Service
CHAT	Checklist for Autism in Toddlers
DE	Department of Education
DEA	Disablement Employment Advisor
DEL	Department for Employment and Learning
DfEE	Department for Education and Employment (now Department for Education and Skills (DfES))
DISCO	Diagnostic Interview for Social and Communication Disorders
DHSSPS	Department of Health, Social Services and Public Safety
DSA	Disabled Students Allowance
DSM-IV	4th edition of the Diagnostic and Statistic Manual of Mental Disorders (American Psychiatric Association)
ELB	Education and Library Board
ESPA	European Services for People with Autism
ETI	Education and Training Inspectorate
HSSB	Health and Social Services Board
HSST	Health and Social Services Trust
IABA	Institute of Applied Behavioural Analysis

ICD	International Classification of Diseases (World Health Organisation)
IEP	Individual Education Plan
LEAP	London Early Autism Project
MLD	Moderate Learning Difficulties
NAS	National Autistic Society
NASEN	National Association for Special Educational Needs
NDDP	New Deal for Disabled People
NECTAS	National Early Childhood Technical Assistance System
NEELB	North Eastern Education and Library Board
NFER	National Foundation for Education Research
NIPPA	Northern Ireland Pre-school Playgroups Association
PAPA	Parents and Professionals and Autism
PEAG	Pre-school Education Advisory Group
PEAT	Parents' Education as Autism Therapists
PECS	Picture Exchange Communication System
PEP R	Psycho-Educational Profile Revised
PSEEP	Pre-School Education Expansion Programme
SEELB	South Eastern Education and Library Board
SELB	Southern Education and Library Board
SEN	Special Educational Needs
SLD	Severe Learning Difficulties
STAAR	Structured Training for Adults with Autism in Roscommon
TEACCH	Treatment and Education of Autistic and related Communications-Handicapped Children
WEAP	Wisconsin Early Autism Project
WELB	Western Education and Library Board

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