

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.