

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