



Report on Autistic Spectrum Disorders

A Comprehensive Report into Identification, Training and Provision focusing on the needs of Children and Young People with an Autistic Spectrum Disorder and their Families within the West Midlands Region

**West Midlands
SEN Regional Partnership**

**Annette English and Jeannette Essex
Regional Facilitators**

Report on Autistic Spectrum Disorders

West Midlands SEN Regional Partnership

Contents:

	Page
1. Foreword	2
2. Terms of Reference	4
3. Methodology	5
4. Definition of Autism	6

Free-standing Sections:

Executive Summary

Section 1: Identification, Assessment and Diagnosis

Section 2: Training

Section 3: Provision

Section 4: Home-based Programmes

Section 5: Analysis of the Carers' Questionnaire returns

Published in 2001 by the West Midlands SEN Regional Partnership. All rights reserved. Local Education Authorities and other non-commercial educational organisations and those employed by them may photocopy this report on condition that the source is acknowledged. All other individuals and organisations should not reproduce or transmit this report, or part of it, by any means including electronic, photocopying, recording or otherwise without the prior permission of the publisher.

Foreword

The West Midlands Regional Co-ordination Project was set up as a consequence of the Government's Green paper "Excellence for all Children" (October 1997).

Encouraging partnerships was a key message of the SEN Green Paper and the subsequent Programme of Action. It is hoped that by working closely together, the Government, local authorities, health, social services, the private and voluntary sectors and parents/carers can better support the education of children and young people with special educational needs.

The West Midlands Project (now known as the West Midlands SEN Regional Partnership) is part of a network of eleven SEN Regional Partnerships that cover the whole of England. Initially the West Midlands project comprised of seven LEAs: Coventry (lead authority), Dudley, Sandwell, Solihull, Walsall, Warwickshire and Wolverhampton. However, in September 1999 membership expanded to include all 14 LEAs in the region and Birmingham, Herefordshire, Shropshire, Staffordshire, Stoke, Telford and Wrekin and Worcestershire joined the project.

The first five 'Phase one' projects, which included the West Midlands, were encouraged by the DfEE to pay particular attention to 'low incidence disabilities'. The West Midlands Project, therefore, decided to focus its work on improving services for children and young people defined as having Autistic Spectrum Disorders (ASDs). There was the resolve, however, to ensure that lessons learnt from this collaboration could transfer to other aspects of SEN planning. The terms of reference for the initial phase of work for the regional co-ordination project can be seen on page 4.

The initial phase of the project's work has led to this report on provision and services for children and young people with an autistic spectrum disorder in the region. The report consists of five 'free-standing' sections that deal with:

- ◆ Identification, assessment and diagnosis
- ◆ Training
- ◆ Provision
- ◆ Home-based Programmes
- ◆ A summary of the Carers' Questionnaire returns.

Excluding appendices, the report comprises of more than 250 pages, with the first three sections alone containing almost sixty recommendations for further action.

An Executive Summary, based upon the findings and recommendations of the substantive report on ASDs, can be downloaded from the Partnership's web-site: www.westmidlandsrcp.org.uk or from the Education Management Information Exchange web-site: <http://www.nfer.ac.uk/emie>

Further copies of the substantive report are also available on the Partnership web-site and from EMIE. Alternatively, master copies are held by key personnel in education, health and social services as well as by every Parent Partnership in the region.

It is anticipated that the project's report will not only inform LEA needs, but will also provide a wealth of information to health, social services and the voluntary sector. It is hoped that each of these groups will consider the implications of the findings, to further improve their services. It is in this spirit of partnership that true improvements can be made to benefit all children and young people with special educational needs and their families.

Terms of Reference

The Project Management Team produced the following terms of reference, which have directed the work of the Regional Facilitators:

1. To develop data collection procedures and mechanisms in relation to Autism, which can be used to inform SEN data collection more widely.
2. To produce recommendations to establish consistency across the pilot region in the identification, assessment and diagnosis of children and young people on the autistic spectrum, including the establishment of joint protocols, between Education, Health and Social Services.
3. To produce costed proposals to the pilot region's LEAs and other agencies, for a range of provision, which would enable children on the autistic spectrum to be maintained within the setting of their family and local community.
4. To produce costed proposals to the pilot region's LEAs and other agencies for the training of teachers and parents to support and complement the proposals for provision, and recommendations on collaborative mechanisms to implement these proposals.
5. To develop and report on the processes necessary for inter-authority collaboration on SEN issues, irrespective of the focus area, in order that the experience gained on this pilot scheme can be applied to problems in the future.

Aims 2, 3, and 4 are addressed in this report. Aims 1 and 5 have been reported on separately in an Interim report to the DfEE in April 2000.

Methodology

Consultative research has been an overarching principle of the methodology employed in every aspect of the West Midlands Regional Co-ordination Project. As a starting point for any evaluation of current practice it was assumed that the real information that would allow a fair and objective summary of needs, lay within the operational field. This in essence, means that a method of challenging the perceptions of service providers needed to be identified.

The 'expertise' in helping to define a way forward in terms of assessment, identification and diagnosis, provision and training needs in the West Midlands, lies with parents/carers, schools, support services, education officers, educational psychologists and colleagues in health and social services. It was important to identify a means of consulting all the 'stakeholders'. Views were sought and discussion generated through a Carers' Questionnaire, a series of workshops, conferences and working parties, individual interviews with both professionals and families, and a sample of school visits. The intention was to both provide a critique of current practice thereby identifying strengths and weaknesses and to identify some examples that might serve as models of good practice to be shared as a basis for developing provision in the future.

A Definition of Autism

Autism is a complex disability that presents many challenges to education, social services and health in terms of understanding, provision and services. It is therefore helpful to include a definition of Autistic Spectrum Disorders (ASDs), as applied throughout our work:

All children and young people on the autistic spectrum have a triad of impairments in common, that is; they all have difficulty to some degree with social interaction, communication and flexible, imaginative thinking. This triad of impairment can lead to differences in learning, thinking and perception that may need to be addressed as special educational needs.

Autism is a wide-ranging disability and can affect those children and young people with profound and/or multiple learning difficulties as well as those with average/high intellectual abilities. What is common with all people with an autistic spectrum disorder, however, is the overall pattern of difficulties in the three core areas of functioning.

The term Autistic Spectrum Disorders (ASDs) in this report, refers to children and young people with Classical or Kanners autism, Asperger syndrome and semantic-pragmatic language disorders.