



Report on Autistic Spectrum Disorders Executive Summary

An Executive Summary of the 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**

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Report on Autistic Spectrum Disorders

West Midlands SEN Regional Partnership

Executive Summary

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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), 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 3.

This initial phase of the project's work has led to a comprehensive 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.

This Executive Summary is based upon the findings and recommendations of the substantive report on ASDs, which 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>

Hard copies of the report are also available from key personnel in every LEA 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 Executive Summary and the substantive 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 Kanner's autism, Asperger's syndrome and semantic-pragmatic language disorders.

Section 1

Identification, Assessment and Diagnosis

Summary and Key Recommendations

There has been much debate within the West Midlands LEAs, about the strengths and difficulties of labelling a child's special educational needs by disability group. However, multi-agency planning can only be effective if it is based on a thorough analysis of need. At present children are classified under educational, medical and social models. A national agreement on definitions would provide a sound foundation for future working together. Identification of ASDs is still often the domain of the medical profession but it is clear that there is a move towards a multi-agency approach in many authorities. Such an approach should lead to earlier access to appropriate services giving families a co-ordinated and comprehensive package of education and care.

Main findings:

- There are no uniform methods of early identification of ASDs across the region. The routine use of the CHAT (Checklist for Autism in Toddlers) by Health Visitors at the 18 month/2 year developmental check is being introduced in some areas of Warwickshire and Staffordshire.
- In order to manage demand pressures on services, criteria for accessing LEA Specialist Support Services may include a need to have a formal diagnosis of ASD. This is unhelpful to those families who receive a late diagnosis and does not encourage early intervention. If resources allowed, the specialist skills available within autism-specific and speech and language services could be used to support children with severe communication disorders/social behaviour difficulties without the need to label.

- A definition of 'intellectual abilities' is often required to access both Learning Disability (Social Services/Health) and Mental Health Services. A significant number of professionals and parents feel that children and young people with Asperger's syndrome or high functioning autism and challenging behaviour are disadvantaged because they do not meet the intellectual criteria for support. It is generally agreed that this group of young people are vulnerable and should be regarded as 'children in need' but they continue to be denied access to services in some authorities because they fail to meet the official definition of having a 'learning disability'. Other professionals feel that the needs of children and young people with autistic spectrum disorders and challenging behaviour should be met within the Child and Adolescent Mental Health Service (CAMHS) teams. However, it is also recognised that not all teams will have the training and expertise to assess those individuals with complex psychological profiles.
- A difficulty with multi-agency working is ownership and initiative. Joint working requires an atmosphere of mutual respect and trust. Issues such as the use of shared models and language, hierarchy, status and different perspectives of need are barriers that can reduce the effectiveness of multi-agency team work.
- The drive to set up multi-agency teams often arises from one or two motivated, committed and interested professionals. If these key people leave then the energy is lost and the ability to sustain momentum is a challenge.
- Funding of services is reliant on separate agency budgets and therefore, because of the changing priorities within education, health and social services, this is a key issue. Ownership and commitment from senior managers and elected members is often lacking but without joint commissioning, service delivery often lacks cohesiveness and is vulnerable to fragmentation.
- There is an unacceptable time delay in identifying ASDs for many children. A failure to identify ASDs at an early stage is often due to a lack of professional awareness of ASDs by non-specialists e.g. Health Visitors, GPs, Nursery staff etc.

- It is difficult to correctly identify the needs of many older students with Asperger syndrome or high functioning autism. Professionals from across the region are concerned that they are receiving more referrals for children/young people within the 8 –12 year old range than previously.
- Time constraints and excessive caseloads mean that multi-agency/multi-disciplinary teams are often not able to carry out what good clinical practice dictates.
- Some professionals have complained that they are under pressure to provide a diagnosis, although there are other factors that may be impinging on the situation. This pressure may result in an incorrect diagnosis because of incomplete evidence.

Recommendations

- It is strongly recommended that a Multi-agency Working Group is set up to establish a set of protocols for identifying children and young people with an ASD which can be adopted across the region. Protocols should be linked to regional management and support guidelines. This will provide a consistent framework for assessment across the region.
- Joint agency databases need to be established, which would fulfil the need for a long-term joint agency planning tool. The Birmingham model is commended as an example of good practice.
- Meaningful collaboration between all agencies should be established at a managerial level in order to achieve joined up thinking and explore the viability of pooled funding. This could be considered by joint care planning teams around the region. Arrangements for assessment, identification and diagnosis should be formally secured through service-level agreements that clearly stipulate the roles and responsibilities of health, social services and education.
- Multi-agency teams should be established across the region through a joint commissioning process and an element of pooled resources. (Reference: *'The*

DoH document 'Partnership in Action', Regulations and Guidance Section 31, Health Act')

- Consistent definitions of ASD/autism etc. need to be agreed between health, social services and education on both a local and national level. This should also apply to future legislation. The Regional Working Party of Identification of ASDs should be asked to address this issue as part of its remit.
- Quality standards for the assessment and diagnosis of ASDs need to be defined regionally based on the NHS Clinical governance framework and learning from the Quality Protects programme. This could be achieved through the establishment of the Regional Working Party.
- Ideally, a joint funding mechanism for training on methods of identification of ASDs and ensuing action plans should be established. Training should be across agencies and jointly run. Integrated training strategies will help professionals from different agencies and disciplines achieve an understanding of the cultural difficulties and differences between their respective organisations.
- Consideration should be given to all multi-agency/multi-disciplinary teams having the same core training e.g. DISCO + ADI. Each team should have at least one professional trained in the use of these identification tools.
- Regional standards for early identification need to be established. These standards should include a training strategy for professionals to ensure early recognition and intervention e.g. systematic use of the CHAT by trained Health Visitors/GPs.
- A training priority is raising awareness of ASDs for tier 1 - primary level staff, so that support and intervention can be provided for the child suspected of an ASD regardless of an actual diagnosis.
- An information pack should be given to families following a diagnosis and follow-up support offered. Ideally this should be followed up with an 'advice and information' session and the opportunity to participate in a programme such as

the National Autistic Society's 'Early Bird'. Information regarding the Early Bird scheme and estimated costings can be found in the substantive report.

- Autism awareness training should be provided for all nurseries. Nurseries should have clear pathways of referrals and excellent communication networks to the relevant multi-agency teams.
- Identification and intervention should be inextricably linked. Identification of an individual's needs as being on the autistic spectrum should always lead to the development of a detailed management/care plan that contains recommendations for future provision and support. It is recommended that regular multi-agency meetings are held to discuss the management of complex children and young people with an ASD. A key-worker should be assigned to every family. They would act as a liaison link for the family and ensure that they receive and understand an explanation of the assessment process. The key worker could be from health, education or social services.
- There should be close liaison between Educational and Clinical Psychologists with discussion regarding the roles and responsibilities of each profession. Specialist skills and knowledge of the family should be matched to each individual situation. Both professions should be represented in the multi-agency diagnostic and management teams.
- A feasibility study should be established, (this might be resourced through the CAMHS modernisation fund, which has the broad brief of promoting mental health in children) to study the benefits of EPs working with CAMHS within a tier 3 assessment, identification and intervention service. (An assumption of the funding arrangements for the CAMHS modernisation fund is that the work will be multidisciplinary, and ensure, as a minimum, the joining up of Local Authority (Education, Schools, SSD) and Health (especially specialist CAMHS).
- The regional multi-agency protocols and quality standards must be evidence-based and regularly evaluated and revised in the light of current research and legislation. The protocols should provide a continually evolving framework for the identification, management and care of children and young people with an ASD and their families living within the West Midlands.

Section 2

Training

Summary and Key recommendations

There appears to be a growing awareness of the special needs of children and young people with autistic spectrum disorders throughout the West Midlands. Several authorities have employed specialist teachers who are able to raise staff awareness of ASDs in schools and colleges. Other staff, (teachers and LSAs) have attended courses run by specialists in their own authorities or by Institutions of Higher Education/Voluntary agencies.

There is a danger, however, that attendance on a short-course on autism is seen as adequate training and that knowledge of one approach will meet the needs of all pupils with an ASD. No one approach will be suitable for all pupils with an ASD and staff need to be able to adapt their knowledge and skills to suit the individual pupil and situation. If staff are unable to do this, then they will need to be able to draw upon the knowledge and expertise of a specialist teacher or educational psychologist.

A survey of the training on offer across the 14 West Midlands LEAs has been compiled into a Training Directory which is available as a separate section of the substantive report.

Main Findings:

- The West Midlands region boasts some excellent training facilities, all offering courses/sessions regarding ASDs. Voluntary agencies also run training courses for staff although most staff training is 'in-house'. There is variation in the quality of courses offered although this can be counteracted by courses being accredited by Institutes of Higher Education where there is ASD expertise.

- Many LEAs do not keep central records of staff training and it is therefore, often difficult to know which schools/staff have any knowledge/expertise in autistic spectrum disorders.
- An understanding of autistic spectrum disorders is essential when working with children and young people with an ASD. A minimum requirement for all staff who work with children and young people on the autistic spectrum is a basic knowledge of the triad of impairments and their educational implications. Effective training is vital to “help allay fears and increase expertise” within schools and support services themselves.
- Staff (schools and support services) are keen to share expertise and ways of working and benefit from regional forums where this can occur.
- Independent schools would welcome closer collaboration with the maintained sector and some could provide valuable sources of additional specialist training for the region.
- Close links between education, social services and health are important for any joint training initiatives.
- Quality time is not commonly made available to either receive or to deliver training. Courses are often offered as twilight sessions which means that all those involved are frequently tired and not at their best. Participation in these types of courses demands self-discipline, self-motivation and utilisation of staff’s own time and these factors restrict take-up of courses.
- Special school heads are concerned that off-site training does not easily generalise into changes in classroom practice and that procedures for cascading new skills throughout the school are complex to construct. Special school heads therefore advocate the development of an ASD-specific package based on the NVQ model, that could be used by in-school trainers.

- Qualifications do not automatically provide a basis for career progression or access to higher education and professional training, consequently there is little incentive in terms of pay or career opportunities to encourage staff to pursue further training.
- There is a wide variance in allocation of standards funding between LEAs. Standards funding for training is directed towards curriculum development/pupil improvement and not towards named disabilities such as autistic spectrum disorders. This makes budgeting for ASD-specific training difficult.
- In smaller LEAs, courses are often focussed predominantly on mainstream school populations.
- Restraint training is still an outstanding and very significant issue within special schools. The issue affects schools' ability to meet the needs of those pupils with an ASD who present challenging behaviours. Consequently many of these pupils are admitted to relatively very expensive independent/non-maintained special schools, often on a residential basis.
- Training across the region is of variable quality – some authorities do not have the specialism to deliver in-house training.
- Families are eager to engage in any training that will increase their ability to understand and support their children, but very few have access to this form of support. Nearly all of the carers who responded to a regional Carers' Questionnaire stated that they had not received any kind of formal training.
- Nearly half of those families who had received training had to fund it themselves. An overwhelming majority of carers felt that the training they received had been helpful, although there was some criticism that the training was not followed up to reflect changing needs.
- Behaviour management is the major source of stress for carers of children with ASDs. Carers emphasised a desperate need for support in developing their skills in managing their child's behaviour.

- Over a third of parents/carers across the region lack awareness of the level of training and specialist knowledge available in their child's school. This lack of information consequently reduces their confidence in the school's ability to meet need.
- A large percentage of carers felt that there was a general awareness of autistic spectrum disorders within their child's placement.

Recommendations

- It is essential that LEAs have a strategic plan for training all staff who work with pupils with an ASD, which is incorporated into their policy on the education and support for children, young people with autism and their families. Ideally, policies should include a commitment to share expertise across the region as a whole in order to promote regional collaboration and the dissemination of good practice.
- A regional policy on training which links into multi-agency planning needs to be devised. The policy should have a clear structure that will provide a comprehensive means of identifying local training needs, beginning with elected members through to highly specialist personnel in health and education. The use of a model such as the National Autistic Society's PAK (Practice, Awareness, Knowledge) (see substantive report appendices) would highlight gaps in awareness, knowledge and practice into which different skill levels of personnel can be matched by appropriate training.
- A regional working group needs to be commissioned to develop a specialist introductory course for those teachers and Learning Support Assistants who work with pupils on the autistic spectrum. This course would cover all of the 'Extension Standards' necessary to work with pupils on the autistic spectrum as described by the Teacher Training Association Standards, TTA Standards – National Special Educational Needs Specialist Standards (Dec.99). The course would then be available on a regional basis, as core training on ASDs and delivered by local multi-agency teams; or alternatively -

- A teacher/trainer with responsibility for ASD training across the region could be employed. This person's sole remit would be to deliver ASD-specific training on a regional basis. It would be intended to deliver training to a multi-agency audience thereby making it appropriate for the post to be jointly funded by health, social services and education. It is a priority that tier 1 health professionals are ASD aware. Section 31A of the Health Act may be used to access pooled funding.
- LEAs could be invited to join the newly created Forum for Regional Education Development (FRED) established through the Regional Health Authority, to advise on and commission training across the health/social care divide. This forum would then provide an opportunity to include educational professionals in joint training initiatives and promote multi-agency working.
- The needs of children and young people with autism are diverse and no one training package will be able to fully meet those needs. A diverse menu of training should be made available across the region.
- It is essential that accurate data is available regarding the knowledge base and expertise in ASDs within schools and pre-school provision in the region. This information must be regularly up dated so that it is current and accurate. Individual LEAs should conduct a skills audit, which will provide the basis for a regional database on current skill levels and training needs. This would inform regional planning and provide a tool for training providers to identify ongoing training needs.
- All provisions (support services, nurseries and schools) should keep a database, (developed within the constraints of the Data Protection Act) which details the knowledge and experience of the schools' staff in relation to ASDs. Ideally this would include a record of training, which distinguishes between professional development courses that lead to qualifications, and one day, or short course, attendance. The information would provide a tool on which to market services and increase parental confidence in a school's provision.
- A compulsion to enroll on accredited HE courses should be a criterion in the selection of key staff requiring ASD expertise. For existing key teaching and

advisory staff, who have not acquired a specialist qualification, priority should be given to encouraging them to enroll on an appropriate course.

- The national network of advisory teachers (Autism) which is facilitated by the West Midlands Autistic Society (WMAS), would be strengthened if it was supported by all LEAs. In addition, members from the West Midlands would benefit from developing a sub-group that would link into any regional, multi-agency, ASD training teams that may exist or emerge. The regional network could act as a Forum to share good practice, where packages/resources are developed.
- Specialist support staff need to have time allocated to keep up to date with new methods of teaching and supporting children with an ASD. Time ought to be made available to share good practice across the region e.g. visits to other schools/ authorities/services as part of their continuing professional development.
- There needs to be Continuing Professional Development for LSAs on the subject of ASDs. This could be through locally run courses that are accredited by an HE facility with ASD expertise. LSAs need a progressive career structure and should be given support for open learning opportunities to gain at least Level 1 (HE) qualifications in ASDs. LSAs supporting pupils with an ASD should be required, through their contract of employment, to complete a level of minimum training that is delivered to a common regional standard.
- Staff should have initial training in ASDs as a precursor to attending ASD 'approach-specific' short courses.
- A rolling programme, across the region, for ASD awareness raising should be prioritised across all pre-school provision and schools.
- Ideally there should be a component of ASD awareness raising in initial teacher training courses, but if not, this should be included in courses run for newly qualified teachers in each authority. All teachers need to have at least an understanding of the triad of impairments in autism and the potential implications for teaching.

- ASD awareness needs to be included within induction programmes for any new LEA Officers (SEN), who may be involved in the decision making process for young people with an ASD, or who have direct contact with families in terms of offering help/advice. This may also be appropriate for some officers already in post who lack confidence in their knowledge of ASDs.
- Whilst performance indicators for school improvement and raising standards focus on the national curriculum e.g. literacy, creative methods of funding initiatives for school improvement against a specific disability should be explored.
- Quality time needs to be identified to deliver training courses. It should be recognised that staff are resistant to giving up evenings and weekends.
- Opportunities to access training on a flexible, local basis need to be identified e.g. distance learning, video and on-line training.
- Participation in a training and support programme such as the Early Bird programme or the National Autistic Society's 'HELP' programme, should be offered to all families, following the identification of an autistic spectrum disorder.
- Training for families must be on-going, as individual needs change according to age and circumstances. All authorities should offer a variety of training courses for parents/carers in the management of ASDs that is delivered by a multiagency team.
- There is a need for siblings' workshops to be set up within easy travelling distance of home – it would be appropriate for the voluntary sector to respond to this challenge in partnership with local Parent Support Groups and Parent Partnership Services. They would play a major role in organising and running the workshops as well as supporting hosts by providing advice on agendas/speakers etc.
- A database of parents/carers' training needs should be compiled on a voluntary basis (a form could be included in an information pack). This would enable targeted training to be set up and advertised via a postal mailing list - this could be done by any, or all of the voluntary agencies working in partnership.

- The Regional Training Directory for staff working with children and young people with an ASD, should be regularly up-dated (at least annually) and be made available to all staff.

- As a pilot to SEN training more generally, a co-ordinated regional website on ASD training could be produced to complement the Directory. The site might provide up-to-date information on training opportunities that are open to school staff and parents/carers throughout the West Midlands region. Opportunities will include those offered by the voluntary sector as well as formal training courses. The website could be further supported by a “Web-Wise” pack. This would double up as a training resource for schools and parents/carers.

Section 3

Provision

Summary and Key Recommendations:

There are many excellent schools in the West Midlands that provide good teaching and support for children on the autistic spectrum. Placements are, however, totally dependent on local circumstances.

Placement pressures often emanate from a combination of parental expectations and the knowledge and expertise of professionals within the decision making cycle and in providers (schools). LEAs have the conflictual task of balancing the ideal against current reality.

The project has identified concerns around mainstream placements. These include challenges in terms of environment; skills and most importantly staff commitment.

Recommendations

In order to provide a cohesive response to the needs of young people with an ASD and their families, the project recommendations on provision conclude that all Local Authorities should have the following in place:

- A multi-agency policy on the provision of services for individuals with an autistic spectrum disorder, which links to a regional policy to be agreed between all members.
- Appropriate educational provision for children and young people with an ASD that ranges from unsupported placements in mainstream to specialist residential schools.
- A process whereby placements will be determined through a thorough assessment of each pupil's individual special educational needs by professionals with knowledge and understanding of autistic spectrum disorders.

- Clear admissions criteria for any autism specific provision, access to which is not necessarily dependent on candidates having either a formal diagnosis of an ASD or a statement of special educational needs. This will enable professionals who have a sound knowledge of ASDs and educational environments to give clear and concise information and advice to parents.
- A consultant Educational Psychologist in every Educational Psychology Service, who is able to provide specialist guidance on the assessment and management of pupils with autistic spectrum disorders. This is in line with the recent report of the Educational Psychology Services Working Group (DfEE, 2000) which emphasises the value different agencies placed on EPs who have a particular specialism.
- Jointly funded Health and Education posts for specialist psychologists should be encouraged, providing a key link for health professionals into the LEA and schools and a mechanism for a more co-ordinated approach to multi-agency working and the development of shared agendas.
- Regional quality standards for provision for pupils with an ASD, which include aspects of the pupil's environment, training standards and support from knowledgeable professionals. A service such as the Autism Accreditation Programme could provide a starting point to creating guidance for a regional accreditation scheme.
- A pre-school programme, which provides a range of strategies and interventions that can be deployed in the home. This will provide parent/carers with the additional skills needed to help their child with an ASD develop. The NAS Early Bird Programme is commended. Intervention should be regularly reviewed with clear criteria for nursery/school entry and/ or continuation of support in the home setting.
- Early specialist intervention that aims to equip the child with the necessary skills to function in a less specialised setting. Enhanced nurseries with staff who have received ASD specific training should be an option open to parents/carers in all authorities. The Walsall pre-school model is commended as it provides children and their families access to specialist staff both in the nursery and home setting.

- Strong home/school partnership arrangements that encourage parents/carers to feel confident in their child's provision. Joint training programmes that encourage parents/carers and school/nursery staff to work together will facilitate shared understanding and positive relationships between home and the educational provision.
- An ASD specialist/s within the LEA's retained special educational needs support service. The discipline should be protected from delegation to schools on the basis that autistic spectrum disorders cover a broad spectrum of need and those children and young people with severe and complex communication disorders or/and challenging behaviours could and should be categorised as a low incidence need - or alternatively -
- A marketing strategy to advertise the ASD expertise of existing staff within the authority's generic support service(s). This would include those teachers who may have completed the Advanced Certificate in Education (Autism). For example, whilst Solihull does not presently offer an ASD specific support service, approximately five of their support teachers have acquired a high level of qualification in the field of ASDs.
- A system that ensures that all learning support assistants (LSAs) allocated to children/young people with an ASD will have received an appropriate level of training. They should also receive ongoing support from other professionals (e.g. specialist teachers or specialist LSAs), who have knowledge and experience in working with children and young people with ASDs (as detailed in section 2, Training).
- A plan that recognises that the needs of individuals with an ASD will change over time, so their educational provision should be flexible and subject to regular review, with the primary aim being to secure inclusive educational provision in readiness for adult life. Planned progression should result in a movement towards less specialist settings rather than to more 'specialised' segregated settings, which is often the case.

- All placements made within the independent/non-maintained sector should be subject to the principles of a Best Value Framework, which as part of its quality standards, includes the implementation of joint protocols. These could be established on a regional, sub-regional or local level. A regional response however, would encourage the sharing of information and allow the West Midlands Care Consortium to play a part in a long-term strategic planning process.

- Consideration should be given to creating small, designated units on a sub-regional basis to respond to the low-incidence need of young people with significant challenging behaviours that are so severe they prevent access to community and very often, independent sector provision.

- The West Midlands region must consider a value for money review of all current placements, which looks at the quality of provision and includes the sharing of data, for example school inspection information and annual review outcomes. The review should include the aim of joint contracting with the West Midlands Childcare Consortium.

Section 4

Home-based Programmes

Summary and Key recommendations

For the purposes of the report, the term ‘home-based programmes’ describes the more unconventional, controversial programmes of intervention, that are commonly delivered within the home environment. These include Applied Behavioural Analysis (ABA)/ Lovaas and Son-Rise Options programmes. Home-based programmes such as Portage are not considered as they are commonly included as part of the long-established pre-school provision in many authorities. Portage is well developed and researched and there is less controversy about children and families being supported using these programmes.

Requests for home-based programmes within the West Midlands is a relatively new phenomenon compared with many other parts of the country where they have become firmly established within a range of provision e.g. Cheshire and Manchester. The project was, therefore, set the task of “analysing existing programmes used to support children with autism: Lovaas, Options Son-Rise, etc”.

As part of this analysis, an Evaluation and Monitoring Working Party was commissioned to respond to the need to ensure consistency in monitoring and evaluation techniques across the region. The Working Party has produced Regional Protocols on Monitoring and Evaluation and a Recommended Operational Guide for LEAs who are responsible for the funding, implementation, monitoring and provision of home-based programmes. These are both described in Section 4 of the substantive report.

Main Findings:

- Over half of the 14 West Midlands LEAs have children following home-based programmes such as Lovaas or Options (9/14 authorities as at June 2000). Of those nine authorities, eight LEAs are funding the programmes.
- Many authorities have invested significant sums of money in ABA/Lovaas type programmes.
- There is a diversity of funding sources which underlines the inequity in decision making throughout the region.
- It is also evident that even when programmes receive funding from LEAs, the responsibility for implementation often rests with the parents. However, all families felt confident that the programme met their child's need.
- Only eight (44%) of the eighteen programmes described by parents in the Carers' Questionnaire returns, were receiving professional support.
- Ten (55%) of the programmes receive no input from health or local authorities.
- There is a general consensus that early intervention in the form of home-based programmes can be a positive way forward in both aiding the individual child's development and in the 'skilling up' of parents in terms of understanding and supporting their child. However, the content, quality, ownership and costs of many home-based programmes leave continuing cause for concern.
- LEAs have to consider the equal opportunities issues that arise from differential costs in provision. For example, a part-time nursery placement (£1000 pa circa) compared to a Lovaas type programme, which can range from £7,500 to £24,000 plus per annum.
- Agreement by West Midlands LEAs to support home-based programmes has, without exception, been on a pilot basis. No Authority has been convinced that the intervention is entirely appropriate. Some LEAs have agreed to home-based

programmes because of a lack of confidence in their existing pre-school provision, but have expressed concerns about their ability to monitor and evaluate the programmes.

- There appears to be a high level of support from professionals to consider alternative forms of intervention e.g. the National Autistic Society's Early Bird Programme.
- In some West Midlands Authorities, an attempt is already being made to increase the practical support families receive after their child's needs have been identified as being on the autistic spectrum through funding staff to attend the Early Bird Programme.

Recommendations

The Monitoring and Evaluation Group recommends to those authorities that do decide to adopt a home-based approach to early intervention that:

- they identify a clear pathway which will support the child's progress into a continuum of provision
- programmes should be part of an overall plan and should not be set up in isolation
- consideration should be given to the use of Learning Support Assistants in terms of training, employment and creative support e.g. supporting an integration programme into pre-school provision at stage 3 of the current Code of Practice
- the transition programme should be driven by and built around, the child's Individual Education Programme. The IEP should be drawn up by the LEA in collaboration with the parents and therapists
- authorities should challenge the need to obtain a 'diagnosis' before children have an entitlement to pre-school support, especially when professionals support the intervention as being in the best interests of the child. Many early intervention

programmes can appropriately focus on a range of communication difficulties that are not necessarily ASD specific

- integration programmes should be planned to cascade newly acquired knowledge and skills throughout the school
- multi-agency links should be established to ensure that all agencies are aware of the programmes and play an appropriate part
- before any programmes are agreed, professionals must be reassured that families have made an informed choice based on early and accurate information about available provision and anticipated outcomes
- families should enter a contract with the funding authority, which specifies methodology, responsibilities and the processes for transferring to maintained school provision and evaluating and monitoring progress
- there is a need to differentiate between home-based programmes and education otherwise
- there is a need to build in a requirement to seek a view from social services on the likely impact the programme will have on the family and whether the working environment is suitable for both the child and the therapists
- the programme objectives should be aimed towards National Curriculum requirements, Early Learning Goals and Foundation Stage Curriculum delivery.
- For those authorities that support families using relatively short, intensive programmes such as Early Bird, further discussion within the region needs to take place to ensure that family support is continued after the completion of the 3-month programme. It is suggested that trained Learning Support Assistants (LSAs) are employed to continue the support to the families until critical targets (such as those agreed by the regional Monitoring and Evaluation Group), have been reached. The LSA would then act as a link with nursery/school staff as the child transferred from home to nursery/school. Ideally this role would be in a

multi-agency context, to ensure that the family have continuity in terms of health, social services and educational input.

- Data collection would be required to evaluate the effectiveness of the approach described above. Results should be fed back to the Monitoring and Evaluation Group as part of a regional remit of monitoring and evaluating home-based programmes.

Section 5

Carers' Views

A recurrent theme of current government policy, is user involvement. A project that did not take into account the perceptions of service users would therefore, be fundamentally flawed. It was thus, right and logical to ask service users to pass a personal judgement on the effectiveness, efficiency and quality of the service(s) that they receive and to ensure that their collective voice is heard.

Whilst it might be possible to target a representative group of carers, the project was committed to ensure that as many people as possible had the opportunity to contribute to the project.

Consequently a very detailed and comprehensive questionnaire was constructed in partnership with the region's Parent Partnership Services and the Voluntary Sector.

The overall aim of the questionnaire was to survey the experiences of parents and carers of children with an ASD from birth to adult hood. The questionnaire included sections on diagnosis; issues relating to educational provision; transport; training; external support; advocacy; transition; and the impact on the family.

The project distributed 2500 questionnaire via: Local Education Authorities, the West Midlands Autistic Society, Parent Partnership Services and Diagnostic specialists. The Questionnaire was marketed through newsletters (WMAS and Afasic), Parent Support Groups, word of mouth and the project's website.

The questionnaire was designed to not only respond to LEA needs, but also to provide a wealth of information about health, social services and the voluntary sector.

Section 5 of the report of the West Midlands SEN Regional Partnership contains an analysis of the completed questionnaires. The project received 625 completed questionnaires from around the region, which is estimated to be a return of at least 30%. This analysis therefore, provides a secure information base upon which to draw conclusions.

A self-review instrument for individual LEAs

The findings of the regional project/partnership have been crystallised in the form of a self-review instrument for individual LEAs. This appears in the table below. It is hoped that its use will generate some interesting and challenging debate.

Self review instrument for LEAs

The findings of the report indicate that the ASD-friendly LEA should provide:

- ✓ Multi-agency diagnoses and assessments, which lead to clear management and care plans
- ✓ An information pack for carers to cover the whole age range 2 to 19, which is distributed at the end of, or during the assessment and diagnostic process
- ✓ A clear Policy on ASDs that includes training and provision
- ✓ A joint database of information that is used as a planning tool between education, health and social services
- ✓ Officers, including EPs, who are ASD aware
- ✓ Parent Partnership Officers who are ASD aware
- ✓ A range of early intervention measures to support pre-school provision, which are implemented in partnership with parents
- ✓ Training programmes to cover the needs of families and school based staff, which are delivered on a flexible basis
- ✓ A policy of whole school awareness raising and an expectation that support staff (LSAs) who work with pupils with ASDs will be supported to undertake specialist training at an appropriate level
- ✓ Clear admissions policies for pupils with an ASD that seek to match identified needs to provision in terms of environment and curriculum
- ✓ A needs led funding mechanism that recognises the diversity of ASDs and their potential impact on the curriculum
- ✓ Specialist support staff with additional ASD-specific qualifications to offer advice and support to school based staff
- ✓ Residential protocols which include health and social services as partners in the decision making process used to place young people in residential settings
- ✓ A resource base that offers information and training materials to support schools and parents in meeting the needs of individuals with an ASD (this could be based in local libraries)
- ✓ Sensitivity to transport needs including ASD-awareness raising where appropriate
- ✓ Locally based parent support groups, which receive LEA support
- ✓ A range of ASD-friendly respite/short break facilities
- ✓ All children/young people with an ASD, allocated a key-worker who co-ordinates input from different agencies
- ✓ A policy agreement with the Speech and Language Therapy service, that makes explicit the criteria for clinical priority for intervention
- ✓ An ongoing system of review and evaluation of the above