

Health Scrutiny Committee Report

Stockport Services for Children and Young People with Autistic Spectrum Disorder

20th February 2007

1.0 Background

1.1 This report gives an overview of local services provided by the Stockport Children and Young People's Directorate, Pennine Care NHS Trust, Stockport NHS Foundation Trust and Stockport PCT for children and young people with autism up to the age of 18. Information is given on the definition of the condition of autism; the local and national policy contexts; prevalence in Stockport; the main services offered and development work to meet the challenge of providing a comprehensive range of complementary provision across the broad spectrum of needs related to autism.

2.0 Definition of Autistic Spectrum Disorder.

2.1 It is important to recognise the significance of the reference to the notion of 'spectrum' as this clearly demonstrates that autism can manifest itself in a very broad range of needs, signs and symptoms. There are, however, a number of common components to ASD summarised as a lifelong developmental disability that affects how a person communicates and relates to people around them. Children with autism have difficulties with every day social interaction; their ability to develop friendships is generally limited, as is their capacity to understand other people's emotional expression. There are often accompanying learning disabilities and general difficulty in decoding verbal and social cues.

2.2 The characteristics described above are traditionally summarised as a 'triad of impairments' in the ability of children to:

- Understand and use non-verbal and verbal communication.
- Understand social behaviour which affects their ability to interact with children and adults.
- Think and behave flexibly; which may be shown in restricted, obsessional or repetitive activities.

2.3 In Stockport there has been a conscious attempt to move away from what may be seen as a 'deficit model' described in 2.2 towards fostering an understanding which views people with an ASD as having a different perspective and experience of the world. This view redirects the focus away from trying to change the child with an ASD. It encourages people to value the child's abilities and the child to develop their interests and activities. Professionals and parents are encouraged to see situations from the child's

point of view, requiring a balanced and emphatic approach necessitating the adoption of specific strategies in relation to specific difficulties. Many children with high functioning ASD have an ability to focus on detail and they may be able to concentrate for long periods on a single activity and therefore often achieve a high level of skill, or work on tasks beyond the point at which others would tire of them.

2.4 Within the higher functioning end of the spectrum some children are diagnosed as having Asperger's Syndrome. Such children typically have fewer language problems and may have relatively high cognitive levels. There may also be physiological aspects of ASD which create different perceptions of sound, sight, smell, touch and taste which affects the responses to these sensations. In the context of the school classroom, for example, background noise, strip lighting or bright colours can cause stress or even physical pain, making it difficult for a child to concentrate and behave appropriately. Blocking out background noise or visual information is often a necessary, albeit difficult, challenge in such circumstances.

2.5 The incidence of diagnosed or assessed ASD in Stockport is consistent with national prevalence data within the range of 9 children per 1000 of the population or 1 child per 130 of the population. This equates to approximately 500 under the age of 17 in Stockport. This prevalence is reflected in Stockport policy documentation, summarised later in this report, as a clear indicator that ASD is a high incidence disability, although the ratio is much lower for those young people with the most severe and complex needs, including challenging behaviour. National data from the DfES indicates that:

- There are around 535,000 people with autism in the UK.
- Boys are four times more likely to develop autism than girls.
- 21% of children with an ASD have been excluded from school at least once.
- 59% of children with Asperger's Syndrome have been bullied.

3.0 National Policy Context.

3.1 The national policy context is framed by the Education Act of 1996 and the revised 'Code of Practices on the Identification and Assessment of Pupils with SEN (2001) which emphasise the importance of having a 'graduated response'. In such a system most pupils make progress within an inclusive and differentiated mainstream curriculum. The wide range of ASD related needs are met with a similarly wide range of strategies that skilled teachers possess and this usually means that those needs are met appropriately, even when they are persistent or complex. The more flexible and responsive the strategies are, the more likely it is that such difficulties will not hinder progress. For most pupils these strategies will come from the resources and expertise already within the mainstream school setting and are described as 'School Action' in the Code of Practice. In a relatively small number of cases it will be necessary to call on external services through 'School Action Plus' and for those with the most complex and exceptional needs a Statement of

SEN may be drafted following a formal statutory assessment process described in the Education Act 1996.

3.2 In addition to Education Legislation, the requirement of the Children Acts of 1989 and 2004 have important implications for all vulnerable children, including those with ASD. The latter of the Acts building upon 'Every Child Matters' (2003) has fundamentally influenced the departmental configuration and delivery of services in Stockport. The advent of the Stockport Children & Young People's Directorate from September 2005 is structured to maximise the opportunities for early identification and intervention; and to ensure the achievement of the five broad outcomes of ECM:

- Staying Safe
- Being Healthy
- Enjoying and Achieving
- Making a Positive Contribution
- Experiencing Economic Well Being

3.3 Although the Children Act (2004) provides the overarching context for the development of services for children and young people, the Government has also persisted in requiring a distinct sub-strategy for children with SEN. This strategy is described in 'Removing Barriers to Achievement' (2004) and sets out a long term change programme over ten years with four main strands:

- Promoting Effective Early Intervention
- Removing Barriers to Learning
- Raising Expectations and Achievements
- Delivering Improvements in Partnership

3.4 The overall national statutory and strategic frameworks were recently criticised in a comprehensive report submitted by an all party parliamentary committee and chaired by Barry Sherman M.P. (June 2006). The report called for greater coherence on the notion of inclusion, a national framework for SEN entitlements, clarity on the role of special schools and highlighted some evidence of paucity of service with particular reference to ASD and Social Emotional and Behavioural Difficulties. The summative conclusion that the current framework is 'not fit for purpose' was refuted by the Government, in a lead taken by Andrew Adonis MP (October 2006). The response reiterated the importance of Removing Barriers to Achievement; the necessity for Local Authorities to develop and maintain a broad continuum of provision and to consider particularly issues related to ASD and SEBD.

4.0 Local Policy Context

4.1 The national local guidance is summarised in a single document 'Policy Framework for the Inclusion of Pupils with SEN 2006/09'. This builds upon the 'Stockport SEN Strategic Development Plan (2003) and 'Achievement for All' (2005). At the centre for local policy is the requirement to remove barriers to learning, rather than the removal of the child or young person. This is

- reflected in the Stockport C&YPD Directorate Strategic Plan (2006-2009) with particular reference to targeting services to remove barriers within the emerging Inclusive and Supportive Communities (ISC).
- 4.2 The Stockport Children and Young People's Disability Partnership (C&YPDisP) has been operational from September 2006 and brings together a range of complementary assessment, inclusion and therapy services into a single operational framework. The work of the C&YPDisP is informed by parents and carers with direct experience of the implications of ASD and SEN and has an increasing focus upon early intervention strategies utilising the more focused diagnosed needs emerging from the increasingly embedded Common Assessment Framework and the associated Children in Need response systems.
- 4.3 The recent policy documents build upon and refresh the Stockport position statement and guidance for schools: 'Support for Children with Autistic Spectrum Disorders' (October 2004) which sets out a range of services detailed in Section 5 of this report. This position statement is rooted in the 'Autistic Spectrum Disorders: Good Practice Guidance' (DfES 2002). This national guidance includes a service checklist for ASD which was used as an audit of services in Stockport as part of the submission of Information to the Joint Area Review held in the Autumn of 2005. The overall judgements of services within the JAR process were positive in respect of the broad spectrum of SEN and inclusion.
- 5.0 ASD Services – C&YP Directorate.
- 5.1 For the purpose of brevity within this report it is appropriate to list, rather than fully describe, the local resources. However, more detailed descriptions and evaluations of effectiveness are available on an individual service basis.
- Stockport Portage Scheme: pre-school, home-based service which assists parents/carers following initial diagnosis of ASD by, for example, GPs or Paediatrician. Referral may be via Health Visitors or as an outcome of a Common Assessment Framework meeting. Parent information packs are available from the Portage Scheme.
 - Opportunity Groups for toddlers with ASD and other SEN as well as children without assessed need exist in a range of locations, including, The Overdale Centre, Charnwood Nursery, Valley School, and there are integrated nurseries at Bredbury Green, Valley School and Charnwood Nursery. The latter is a private integrated nursery and family Centre, which receives funding from the LA for children with ASD. Specialised help and support for parents and a Toy Library are also available.
 - Stockport Special Schools: all six maintained schools have experience in meeting ASD. There are specialist classroom areas at Valley School and Lisburne School now has a significant proportion of the pupil population with an ASD diagnosis.

Additionally, there are independent local providers that contribute an important element to Stockport continuum of provision for ore complex ASD. Notably, the service provided under the auspices of the Together Trust through the Inscape Centre for Autism and INCA. The latter provides specialist training, resources and advice to mainstream schools and support for individual children on an outreach consultancy basis.

- Mainstream Schools with Resourced Provision: there are twelve Primary Schools with a range of resource basis, special classes or units and seven of the fourteen High Schools with resourced provision, designated SEN status or a unit. These schools provide for a broad range of SEN and a number of these have developed knowledge, skills and experience in meeting ASD. Commencing in September 2007 it is anticipated that new provision will be available in a designated High School for a small group of pupils with high functioning ASD within a dedicated resource base with access to specialist staff.
- Inclusion Co-ordinators: There are two primary and one secondary INCo to support the links between the special and mainstream sectors and to encourage and disseminate good practice with particular reference to complex learning difficulties, including ASD.
- Inclusion services: There are specialist trained ASD staff in a number of the C&YPD Inclusion Service Teams. Principally, these are the Education Psychology Service, Learning Support Service, Sensory Support Service, Primary and Secondary Behaviour Services, Pendlebury Unit, as well as the Occupational and Speech and Language Therapy Services recently integrated into the Disabilities Partnership described earlier in this report.

Further training is to be undertaken in Autism Diagnostic Observation Schedule (ADOS) by up to six members of the EPS and two other staff selected from the teams listed above. This training will enhance timely multi-agency assessments and appropriate interventions.

- Further Education Colleges: The three mainstream colleges have growing experience of SEN, including ASD. This is complemented by 16-19 provision at Heaton School and 16-21 provision at Bridge College which is part of the Together Trust.
- ASD Partnership Project: commenced September 2006 to enhance a number of services described above and which represents an important new development through partnership between Stockport C&YP Directorate and the Primary Care Trust and Foundation Trust of the NHS. The project bridges all services to ensure effective practice for children aged 8-14 who have been diagnosed with ASD. Parents are employed as co-trainers to assist the project team. There is a particular focus on sharing practice between home and school, multi-agency training and the promotion of autism friendly environments. Individual support packages

or interventions last up to six months with the project team planning a smooth link to existing services following the intervention.

- 5.2 At the time of writing this report there is approximately £300k. invested in family respite care and £240k. for direct payments under the Disability Social Care initiative. There are 120 families in receipt of direct payments; 16 receiving funding for overnight respite; 53 receiving funding for Specialist Outreach respite and approximately 30 Service Level Agreements for respite services, some of which are joint C&YPD and PCT funded.
- 6.0 ASD Services – Health Provision
- 6.1 The health provision with regard to ASD begins early in a child's life as an early clear diagnosis provides the best opportunity to help families and children deal with the communication and behavioural difficulties a child might have. The Care pathways to access services are crucial to ensure that children receive services in a timely manner as required by the Children's National Service Framework 2004.
- 6.2 The Health Visiting staff have been trained in a variety of techniques that help access the communication skills of young children. These include the SOGS (Schedule of Growing Skills), Talking Together programme, aimed at improving parent child communication, and the CHAT (Checklist for Autism in Children), which is an early diagnostic test that can be used to screen all young children.
- 6.3 Following these tests children can be referred to more specialist services for diagnosis, as the test could indicate developmental delay as well as Austistic Spectrum Disorders. In Stockport, these young children usually under school age are referred either to the paediatricians, via the Community Disability team or their GP. This can enable an early diagnosis and then appropriate interventions to support a child either through Portage Services in Education or through specific Speech and Language interventions to improve the child's communication difficulties. This pathway works well with an integrated multi agency approach operating. The Care Pathway 2 is appended to this report for information.
- 6.4 Not all developmental and communication difficulties are evident in the pre-school phase and this can be the situation with children who have ASD. It may only be in the early school years that such difficulties appear for the first time. The majority of children identified are then referred via the education setting in conjunction with the Educational Psychology Service to the Speech and Language Service where there may be a waiting list for appointments.
- 6.5 Children who have not been identified and referred from their school and who are presenting behavioural or communication difficulties at home can be referred through the General Practitioner to the Child and Family Mental Health Service based at Tree House. The Speech and Language Service and the Child and Family Mental Health Service are currently the only services

that can provide a diagnosis of SD for school aged children and this can lead to delays in accessing appropriate on-going services.

- 6.6 In recent years there have been recruitment difficulties with reference to Child Psychiatrists within the Child and Adolescent Mental Health Service (CAMHS). This has been resolved within the last twelve months following a recruitment programme undertaken by Pennine Care NHS Mental Health Trust. Child Psychiatrists are now in place and are providing a service as well as facilitating the multi agency ADOS training, referred to earlier in this report, to aid the process of diagnosis.
- 6.7 The CAMHS Strategy Group for Stockport also made resources available in 2005 for the PCT to appoint two workers to provide parenting and family support to families whose children have an ASD diagnosis. This has gone some way to reducing the service gap, although some families continue to have delayed access to timely interventions.
- 6.8 With reference to children with ASD who also have diagnosed learning difficulties, there is an on-going local challenge to meet the Departmental Health Service requirements. To meet this challenge a multi agency group was established to try and improve the care pathways to access services and to reduce the blockages and waiting lists for services. This group involved staff from Health, CAMHS, PCT Children Social Care and Education staff and the work that they have done has identified improved care pathways and these are included in this report as Care Pathway 2 Care Pathway 3.
- 6.9 The implementation of these care pathways will require some alteration of roles and extra training for some professionals. The care pathway requires a virtual multi disciplinary team or team around the child being developed so that the professional already involved with the child would undertake ADOS assessments and receive support and training from other professionals. No single professional would make a diagnosis but this would be in conjunction with others. Where there are more complex issues the child could be referred for more specialist interventions. This would enable the scarce health resources of Speech and Language therapy and Child Psychiatry to be used for the most challenging children with the most complex needs.
- 6.10 The implementation of the care pathways will reduce waiting times for access to support and interventions. However, there remains a challenge locally to fully meet the Departmental of Health targets and in recognition of this the PCT has made a bid in the current LDP 2007 process for increased resources for Speech and Language Therapy, Child Psychology and Child Psychiatry Time and social work time. This would enable children and families, who have long term problems to access the therapeutic and long term support that is necessary to help families cope with their child's long term difficulties.
- 6.11 In addition to the development of specialised services there are twenty-one Health Centres and Clinics in Stockport with information and advice related to ASD and referral pathways into more specialists services where appropriate

7.0 Employment Services

7.1 There are two main Stockport services:

- Disability Employment Advisers to aid both employers and employees in good practice; awareness raising of ASD and other needs; adaptations and work placement schemes.
- Connexions provide a support service from 13 to 25 with a key aim of enabling all young people to make a successful transition to settled employment.

8.0 Leisure and Voluntary Sector Provision

8.1 The importance of leisure services and voluntary sector provision for young people with ASD is critical to provide opportunities for peer interaction and enable families some respite from care demands. Such service in Stockport include:

- Children's Able Bodied and Disabled Sports (CADS)
- Stockport Dolphins Swimming Club
- Holiday play schemes
- Leisure Link
- Signpost Stockport for Carers
- Youthful Minds

9.0 Recommendations

9.1 That the Health Scrutiny Committee notes the report.

9.2 That the Health Scrutiny Committee schedules subsequent reports into the meeting timetable with a particular focus upon key aspects of ASD service provision for more detailed focused outcome analysis.