

**EDUCATION AND CHILDREN
OVERVIEW AND SCRUTINY BOARD**

TASK AND FINISH GROUP



**A REVIEW OF SERVICES WITHIN SOLIHULL FOR
CHILDREN AND YOUNG PEOPLE
WITH AN AUTISM SPECTRUM DISORDER
AND THEIR FAMILIES**

SEPTEMBER 2006

**Education and Children’s SEN and Inclusion Task and Finish Group
Inquiry: Delivering Inclusion through Partnership
Focus: Autism Spectrum Disorders**

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1 Foreword

1.1 A Word from the Chair

In publishing this report I must thank all Members of the Task and Finish Group for all of their work during the period of the review. On setting and agreeing the Group's terms of reference it became quite apparent that the scope of the review would transcend two municipal years.

Perhaps the catalyst for the review was Solihull's Inclusion and Access Summer Conference, July 2004, entitled 'Hard Choices'. The conference brought together, in one conference hall, representatives from every school in Solihull – special educational needs co-ordinators, teachers, governors and head teachers, as well as officers from the Local Authority and educational specialists. The themes of better and closer inter agency workings, as well as the need for early interventions were identified as paramount.

Members devoted a great deal of time to a subject all were passionate about; undertaking witness and information gathering sessions and site visits.

I also thank the service users who gave their experience to the Task and Finish Group. The parents and guardians provided their evidence with great clarity and purpose, not being afraid to provide constructive criticisms where it was necessary. All Task and Finish Group members found the evidence from parents and guardians especially valuable.

The Task and Finish Group also recognised the value of the professionals working in the service. We thank officers, whether Local Authority or Health Service based, their passion to serve the children is clearly identified.

Ken Hawkins
Chair of SEN and Inclusion Task and Finish Group

1.2 Task and Finish Group Membership

This inquiry began in December 2004 and completed its work in December 2005, therefore spanning two municipal years.

Membership of the SEN and Inclusion Task and Finish Group included:

2004:

- Cllr Ken Hawkins (Chair)
- Cllr Graham Craig
- Cllr Norman Davies
- Cllr Dr Peter Lea
- Cllr Mike Robinson
- Governor Representative, Anne Forder
- Mrs Bernadette Adams, representing the Parent's Voice

2005:

- Cllr Ken Hawkins (Chair)
- Cllr Gary Allport
- Cllr Graham Craig
- Cllr Barbara Harber
- Cllr Theresa Tedd
- Governor Representative, Susan Weaver
- Mrs Bernadette Adams, representing the Parent's Voice

2 Terms of Reference

<p>Purpose:</p>	<p>Through a thematic review of provision for children and young people with an Autistic Spectrum Disorder, use a select inquiry model to scrutinise partnership working, and report findings and recommendations to the Overview and Scrutiny Board</p>
<p>Terms of Reference:</p>	<p>To investigate the effectiveness of partnership working across all agencies and disciplines, specifically those that deliver services for children, young people with an ASD and the experiences of their families.</p> <p>Through stakeholder involvement and consultation, the Task and finish Group will consider the following key areas of inquiry:</p> <ul style="list-style-type: none"> ▪ National perspective – benchmarking data and identifying good practice ▪ Service Users and Family experiences ▪ Processes for Identification, Intervention and Support ▪ Internal Partnership working ▪ Provision – identifying good practice and areas for improvement ▪ Financial issues – (using the principles of Best Value) focus on overall Council expenditure on both care and education provision, specifically focusing on expenditure and outcomes of children/young people placed outside of the Borough. <p>Expected Outcomes: <i>(informed by the Council’s Vision and Values, the Government’s Strategy for SEN – removing Barriers to Achievement and Every Child Matters)</i></p> <ul style="list-style-type: none"> ▪ Improved parental confidence ▪ Integrated approach to early education and childcare ▪ Effective implementation of the Early Support Programme for Disabled Children 0-3 ▪ Integrated health, education and social care services are organised around the needs of children, young people and their families ▪ Council resources are used effectively and processes for identification, assessment and intervention are streamlined ▪ Reduced reliance on external residential placements ▪ Clear role for special schools ▪ Schools working together to support inclusion
<p>Reporting Mechanisms:</p>	<p>Overview and Scrutiny Board standing item</p>
<p>Meeting Cycle:</p>	<p>Six weekly, plus extraordinary meetings and field work as necessary</p>

3 Introduction

In August 2002, Solihull MBC (the Council) commissioned a comprehensive review of Special Educational Needs (SEN). In defining the scope of the review, consideration was given to the complexity of the task in terms of its breadth and feasibility.

It was acknowledged that SEN in its broadest sense incorporates services provided by a wide range of partners. Support services include those delivered by the Council, the Primary Care Trust, Solihull's Parent Partnership Services (known as SNAP locally) and a range of voluntary and charitable groups.

Provision made within the Borough covers a wide range of settings. These include family homes, nurseries, mainstream schools, additionally resourced centres and special schools. In addition children attend a variety of different types of schools including those maintained by other Local Authorities (LAs), the independent or non-maintained sector and both mainstream and specialist colleges of further education (FE). A number of children and young people who are looked after by the LA are placed in residential settings, some of which offer both health services and education. It was therefore agreed that the Council needed to adopt a thematic approach to the review of Special Educational Needs, systematically working through each of the four categories of need identified within the SEN Code of Practice. It was decided that the review would be 'customer focused' and cut cross the whole range of Council Services, involving the full range of partners thus extending well beyond educational issues.

The first review focused on 'Support Services for Children and Young People Experiencing Emotional, Social and Behavioural Difficulties'. The review was conducted by a Task and Finish Group appointed by the Education and Children's Overview and Scrutiny Board. This work was completed in June 2003, resulting in a well-received comprehensive report that has been used to implement a robust strategy for improving services for this group of vulnerable young people.

However, the Inclusion and Access Task and Finish Group was committed to ensuring that its work did not stop there and has continued its focus on SEN, scrutinising the change programme whilst ensuring best value services. The Hard Choices Inclusion Conference held in July 2004, provided a mandate for radical change in the delivery of services within the Borough. It highlighted the need to respond to early intervention and identification and strengthen partnership working across all agencies.

Consequently, Elected Members resolved to conduct an investigation into the effectiveness of partnership working across all agencies and disciplines within the Borough, once again using a thematic theme. They identified the needs of children and young people with an Autism Spectrum Disorder (ASD) as the most pressing area for investigation and committed once again to focusing the inquiry on the experiences of children, young people and their families.

4 Key Findings and Recommendations

The range of evidence provided by parents and professionals proved to be remarkably consistent in terms of the issues highlighted and the priorities identified for development or change. It was therefore pleasing to Members to discover that both service providers and service users took advantage of this review to celebrate the many good areas of practice and partnership, whilst being able to simultaneously provide an honest appraisal of gaps in local services and provision and thereby identify priority areas for improvement.

In summary, the review highlighted the diverse and complex range of needs of children and young people with an ASD. It quickly became apparent that the Borough needs to offer a 'continuum of support to meet that continuum of need'. ASD is a pervasive development disorder that has a major impact on the whole family, including siblings, grandparents and the extended family unit. The review has highlighted the need to secure effective partnership working across all services and agencies in order to respond to this range of challenging needs.

It is expected that the key recommendations will form part of a costed action plan drawn together by the full range of partners, with assigned responsibilities for delivery, monitoring and review.

Key Findings:

- The services and support provided in reaching a diagnosis within the Borough were good, but post diagnostic specialist support or advice for parents is limited, and there is a long waiting list for referrals to the Meadow Centre and speech and language therapy – (it is recognised that there is a strategy in place to deal with this).
- Many parents referred to their experiences of 'breaking the news' and pleaded that this is done with sensitivity and backed up with ongoing emotional and physical support. Parents do not only want to be told what the diagnosis is, but want to know what they need to do about it and who to contact for advice, support and signposting to services. They are also clear that they want advice on educational provision from an educationalist.
- Many parents stressed the feeling of isolation when they are 'discharged' from the Meadow Centre. They have built up relationships with professionals that they trust and miss that ongoing support. They feel that they need a care pathway that supports the whole family in an holistic way post diagnosis.
- The post diagnosis period is a critical time for a family. Family's need to connect with an educational professional as quickly as possible following diagnosis to provide reassurance on provision.

- The role and importance of the extended family has to be taken into account at every stage, parents pointed out that grandparents grieve too. Consequently there is a need for professionals to include support and advice for siblings and the extended family unit.
- Many parents cited examples of home based issues that they were struggling to deal with. Behaviour management was high on the list; Parents felt that they needed training to deal with their child's communication, self-help, behaviour, anxieties and social skills and that this training needed to be updated as needs changed and the child matures.
- Parents highlighted the need to provide home-based support and respite/short-break opportunities. More importantly, they argued the need for professionals to believe them when they say that behaviour at home is difficult even though it is manageable in school.
- There was concern that some parents that are not articulate or do not understand the system will find it very difficult to access services.
- It is clear that for a range of reasons, families vary greatly in their resilience and coping strategies. However, it would appear on the balance of the evidence presented that despite the needs of the individual child being equal, services prioritise families under stress when allocating resources.
- Parents want specialist pre-school provision that links with the home and early years setting, with a planned transitional arrangement into school. Some parents were disappointed that there is no option to assist parents who would like to choose a home based programme such as ABA or Son-Rise Option in preference to school based provision.
- Parents want their child to be educated within the community. Many of them understood the financial arguments for securing local provision and raised questions about the efficient use of resources in terms of the costs associated with supporting external provision.
- Parents of young people with a diagnosis of Asperger Syndrome were the most dissatisfied group in terms of educational provision. They articulated significant concerns about the appropriateness of a mainstream school secondary placement socially and highlighted the inappropriateness of a special school academically. They were concerned that there appeared to be a gap in specialist local provision.
- Young people with Asperger Syndrome are at high risk of suffering severe mental health problems if their needs are not identified and met early. The consequences for the individual and their family are

significant and the financial cost to agencies of responding to a crisis is prohibitive.

- Young people with Asperger Syndrome need specialist support and counselling to come to terms with and understand the implications of their disability. Despite an average or above average IQ, this group of young people are extremely vulnerable in society.
- There was praise for some specialist units at primary schools, but a feeling that adequate provision was not available at secondary level within Solihull. There is a spectrum of need and therefore a range of education settings are needed to cater for this.
- It was recognised that the statutory assessment process is not responsive enough to target resources to high level need before a school placement breaks down. The consequential costs to the child, family school and the LA are often in excess of an early preventative intervention. Failure to target support at both the school and the family leaves a child vulnerable to failure.
- Staff awareness of ASD is critical to a child's success in school. Appropriate training is paramount and will enable staff to respond appropriately, pre-empt difficulties, reduce anxieties, manage behaviour and therefore improve attendance and attainment.
- It was emphasised that the environment in mainstream schools can be difficult for children with an autism spectrum disorder, it was felt that there is a need for the provision of 'chill out' rooms and quiet areas.
- There were many accolades for special school provision especially the staff at Reynolds Cross School who were seen by parents as experts in the field who truly understood family needs.
- Earlier accurate identification of need could prevent the use of inappropriate provision and teaching strategies, thus reducing the potential for failure and the consequences of expensive out-of-Borough placement costs.
- It was argued that the perceived lack of expertise within the Borough at operational level has a significant negative impact on the progress of children with an ASD as well as the staff providing support. This represents an ineffective use of resources.
- Young people with an ASD are vulnerable within the criminal justice system and require strong advocacy support. It is recognised that there is a relatively high rate of suicide amongst young people with Asperger Syndrome nationally, yet this group despite their vulnerability do not have access to disability services.

Recommendations:

- There is an urgent need to develop a continuous care and education pathway for children and families, secured by a parallel continuum of provision. This should be based on the principals of Solihull's Family Support Model and have at its heart a designated lead professional/key worker. The model should link securely to the assessment and diagnostic processes of the Meadow Centre.
- A clear and active partnership needs to be established at a strategic and operational level across health, education and social care, to deliver whole family support integrating the delivery of health, education and care.
- An early intervention programme should be re-established in Solihull incorporating the principles of the 'Early Bird Programme' enabling trained inclusion support workers to be deployed to continue the support to the families and act as a link with nursery/school staff as the child transfers from home to nursery/school. This role should be developed within a multi-agency context, to ensure that the family have continuity of holistic support in terms of health, social care and educational input.
- An integrated workforce training strategy should be developed as a matter of urgency that encompasses the holistic needs of children/young people, parents/carers and the whole range of professionals working within health, education, social care and any other relevant service.
- Measures should be taken and maintained to address excessive waiting times for assessment and diagnosis.
- The needs of children and young people with an ASD and the impact that has on families must be considered by specialist services who currently limit access on the basis of IQ in order to address perceived inequalities and fill a significant gap in support.
- A comprehensive targeted training/ASD awareness programme must be put into place to address the general lack of understanding of ASD **at a whole school level.**
- Schools need to fully understand and respond to their responsibilities under the Disability Discrimination Act, to make reasonable adjustments and recognise the specific needs of young people with an ASD. They should also consider the environmental needs of pupils with an ASD in reviewing their access plans. They should not use disciplinary processes including exclusion (formal and informal) as their first response to inappropriate behaviour.

- The obvious gaps in specialist educational provision within the Borough must be addressed, particularly in relation to early years and Asperger Syndrome. Provision should be expanded to include the establishment of specific, additionally resourced specialist centres for pupils with significant needs to provide educational health and therapeutic interventions plus family services at both primary and secondary level.
- Schools should be supported generally in achieving an ASD friendly environment that offers:
 - Individualised learning areas
 - A place of refuge in order to take time out from the pressures of the classroom
 - Alternative provision for lunchtimes to provide a safe haven or quiet area.
 - Lunchtime clubs to address social communication difficulties and improve self-esteem, incorporating 'circle of friends'
 - Peer mentoring schemes
 - Awareness raising for other pupils.
 - Appropriate planning and preparation for change and transition involving both pupils and their parents
 - An enabling interface between parents and school so that common management strategies can be implemented
- An ASD specific resource centre to be accessed by both parents and professionals should be created. This could be used as both a training and access point for advice, information and tangible resources (videos, internet, books etc). This would be ideally delivered from a special school base.
- Further efforts should be made to expand and support regular and relevant parent support groups with the aim of bringing together appropriate groups with matched needs in an accessible way. It will be important to consult parents on their needs and requirements. This should build on the already substantial efforts of SNAP and compliment the new initiatives recently instigated at the Meadow Centre.

5 Methodology

5.1 Awareness Raising

Autism Spectrum Disorders describe a complex range of needs that are all too often stereotyped or misunderstood. Consequently, Members were sensitive to the need to ensure that they all had a reasonable level of understanding of ASD in order to prepare themselves to receive and understand evidence from families and a range of professionals.

The review therefore began with an awareness training session that enabled Members to grasp the impact that ASD can have not only on the child or young person concerned but also on their whole family network. They had an introduction to the strategies commonly employed to support young people with an ASD both in school and in the community. They also received data on prevalence and achieved an understanding of the potential social isolation experienced by many young people with an ASD especially those with Asperger Syndrome.

Members were placed in situations where they were made to feel anxious and uncomfortable with their surroundings, they were presented information in a way that was difficult to follow or understand and heard case studies from young people describing their feelings and emotions.

This meant that Members felt better placed to empathise with some of the very personal information that parents shared, whilst also appreciating the diverse range of needs and the individuality of the impact of the disorder. Above all, they began the inquiry with an understanding that ASD describes a continuum of need that demands a continuum of support and provision and has a major impact on the whole family.

5.2 Call for Evidence

The Task and Finish Group adopted a select committee model for the investigation. This meant that they formally invited people and organisations with an interest in the issue to provide written evidence to the inquiry. Target groups included children, young people and their families; school based staff; support services; health and social care professionals; voluntary groups and all those who were identified as responsible for delivering Council services. It was also made clear that anyone who wanted to share their experiences and ideas on how to improve services, particularly in relation to how well they felt professionals worked together in partnership to deliver services to families and schools were encouraged to do so.

Guidance on submitting evidence was provided alongside a proforma to complete for ease of response (see appendix (i)), although it was stressed that evidence would be welcomed in any format.

5.3 Oral Evidence

It was recognised that the review had to be managed within a constrained timescale. Consequently, it was intended to invite some of those who had submitted written evidence, to give oral evidence at a witness session. However, in the event the level of passion and commitment from families and professionals proved to be over-whelming. This necessitated an extension of the 'evidence gathering' timescale, and an increase in the number of planned meetings.

In addition, the Task and Finish Group also arranged a series of formal and informal seminars with experts.

5.4 Field Visits

The group committed to conduct site visits to see how things worked in practice and how other Council's approach similar problems.

Examples of those visits included:

- Home visits
- The Meadow Centre
- Solihull's Multi-Agency ASD Working Group
- Special Schools
- Warwickshire, Local Authority
- Worcestershire, Local Authority

All of the evidence base including written submissions and records of meetings and field trips were recorded on the Members web-site. This provided ease of access and ensured that all of the evidence was taken into account within the content of this report, and consequently informed the findings and recommendations of this review.

6 Definition of Autism

Autism is a complex disability that presents many challenges to education, social care and health in terms of understanding, provision and services. It is therefore helpful to include a definition of autism spectrum disorders as applied to this inquiry.

All children and young people on the autism 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 difficulties 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 autism spectrum disorder, however, is the overall pattern of difficulties in the three core areas of functioning (English/Essex).

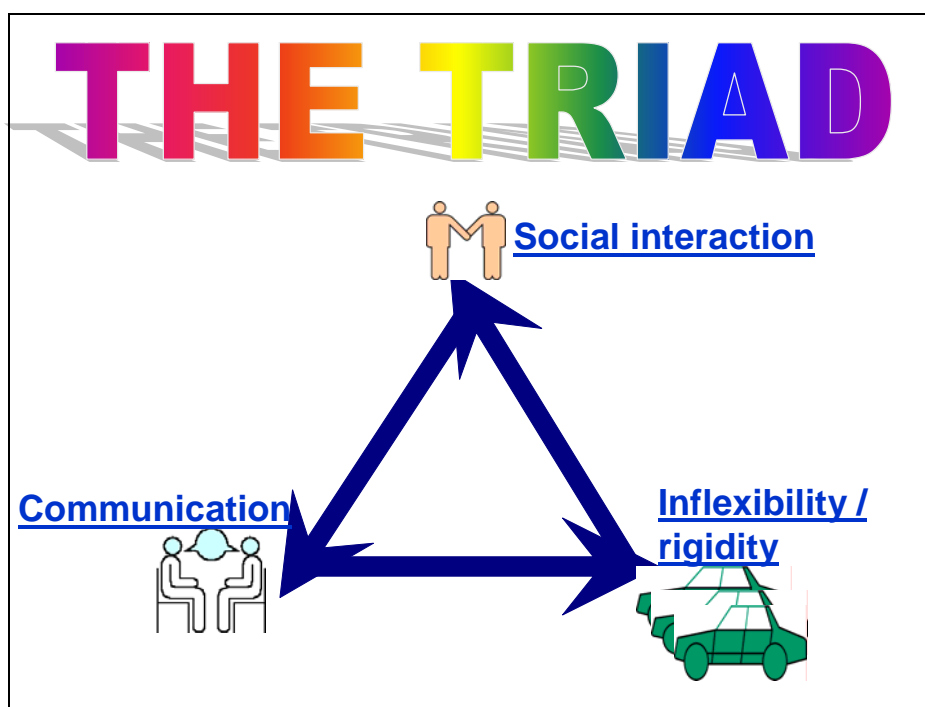


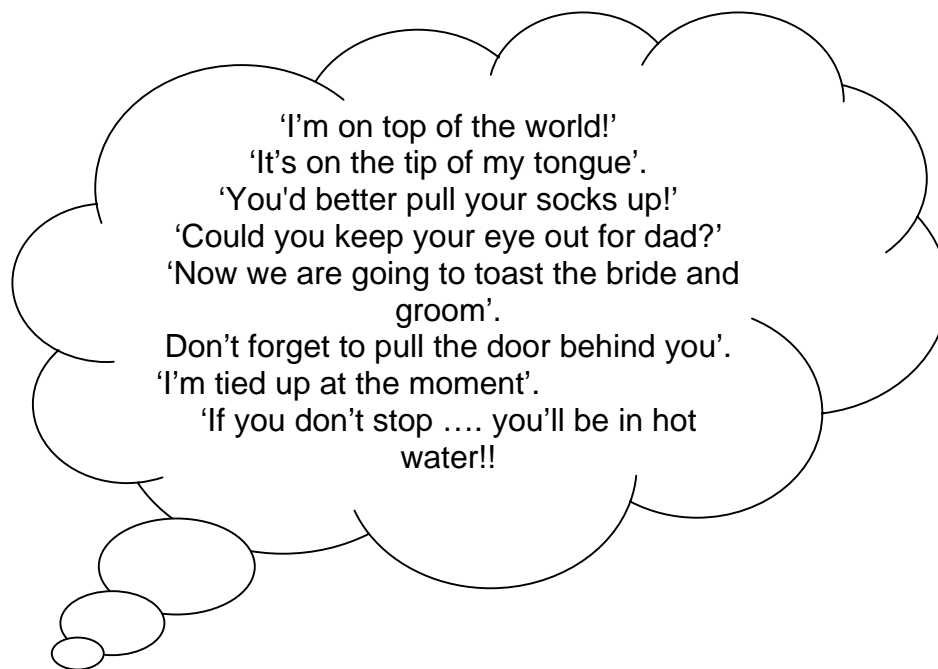
Fig 1 Source: West Midlands Regional Partnership, Presentation Dec 2004

The term Autism Spectrum Disorders (ASDs) in this report, refers to children and young people with Classical or Kanners Autism and Asperger Syndrome.

We wish to thank Annette English, Regional Facilitator of The West Midlands Regional SEN Partnership for providing the following information to assist Members and readers of this report in their understanding of ASD.

People with an ASD may experience difficulty in social communication because they:

Have difficulty in making sense of and using all aspects of communication ie verbal and non verbal. This can range from little or no spoken language to those who appear articulate but lack understanding of body language eg tone of voice, facial expression. They may demonstrate a literal, pedantic, concrete understanding of language and use of words and have limited content of speech. Phrases that would not make sense to them and cause them to misunderstand could include:



People with an ASD may experience difficulty in social interaction because they:

Appear to be aloof and indifferent to other people. They may passively accept social contact and appear spontaneous but in an odd, inappropriate, or repetitive way with little or no attention to responses. Interactions tend to be 'one way traffic' ie not reciprocal and they might display a lack of empathy (Theory of Mind). Consequently they typically have difficulty in:

- predicting others' behaviour
- understanding that behaviour affects how others think or feel
- taking into account what others know or can be expected to know
- sharing of attention, leading to 'odd' comments
- reading and reacting to the listener's level of interest in what is being said.

People with an ASD may appear inflexible/rigid because they:

- display rituals and obsessions, and an insistence on sameness
- have difficulty with creative, open-ended activities, and more abstract ideas
- display rigidity and inflexibility in thinking and behaviour
- have a restricted range of interests and skills which they pursue in a repetitive manner.

7 Section 1 – Families

7.1 Children and Young People's Views

The Task and Finish Group are sensitive to the fact that children and young people were pre-dominantly represented by their families, SNAP and a range of professionals, all of whom demonstrated an excellent advocacy role. However, Members very much welcomed direct evidence from two very able and articulate young people who not only wanted to advocate for themselves, but for their peers too. They did much to enable the group to begin to understand life as a young person with Asperger Syndrome.

Oral Evidence:

Matthew: Is a 16 year old young man with Asperger Syndrome who made a very impressive personal presentation to Members. He related his school experiences and described the impact that his transition from primary to secondary school had on his life. Matthew highlighted the difficulties he had in coping with a secondary school environment, he struggled with school organisation, attitudes of teachers, and the behaviour and noise levels of his peers. He was critical of the lack of understanding of ASD in mainstream and lobbied hard for targeted training and flexibility of rules at school level.

Matthew described his own attempts to secure a 'haven' within the school and expressed frustration that the access criteria for the school's social inclusion unit prevented him from attending on a permanent basis. In the end Matthew self-excluded himself because he experienced high levels of anxiety and could not face going to school.

He described the impact that this experience had had on his mental health and therefore family life. He highlighted teacher attitudes; lack of training, alternative provision outside of the mainstream classroom for able ASD and a need to listen to young people as issues to be addressed. He also highlighted that some pupils experience a break in school based education of 6-9 months because of gaps in provision. Matthew believed that his time at the Triple Crown PRU enabled him to progress academically and go on to attend a specialist college. He could not understand why young people could not simply transfer to the Triple Crown to complete their school career.

Written Evidence:

Zoe wrote: I am a 16 year old young person diagnosed with Autism, Semantic Pragmatic Disorder and Dyspraxia. For myself, and many others on the autism spectrum it is not acknowledged that the sensory difficulties we experience in a busy environment actually hurts us. It prevents me from processing information, I lose the ability to verbally communicate or I use the wrong words – we are therefore either 'ignorant' or 'cheeky'? We are actually neither; we are struggling in an alien world and made to fit in without the support and understanding that we really need. I learn to 'act normal' but it hurts.

This is how it worked for me. After my exclusion I was out of school and my mom found a school with an inclusion unit – my safe place. A teacher at the school was identified to come into the home to get to know me – you see for some people on the autism spectrum new staff have to be a part of the fixtures and fittings in order for us to be able to relate well to them. Change has to be facilitated. I was slowly integrated back into school.

The school has the best SENCO in the world. With the help of her educational psychologist she worked really hard with my mom to understand the difficulties of this busy environment and how it affected me. She gives the best support and when it goes wrong and it does go wrong, she works really hard with mom and me to make it right. We never see this as failure we just see it as starting again.

It has made a difference for me I took my GCSE English Literature a year early and got a C and I am now studying an AS level a year early. I do have a learning difficulty because I have difficulty learning when taught in a non-autistic way. Can you learn people to help us please?

Donna Williams helped me and mom to work out where I had difficulties.

- I can't always keep up with processing information as quick as others
- I can't always do things for myself, by myself or as myself especially when gripped with exposure anxiety
- I can't always look at you and hear you with the bombardment of sensory issues – sight, sound, smell, touch, taste
- Eye contact is a problem to me simply because I don't like eyes
- I can't deal with some environments because I am hypersensitive
- I can't deal with change as well as you do
- I have no idea what a Triad of Impairment means other than people have problems communicating with me and do not know how to help me socialise

Finally, the following poem was presented by a parent as part of their evidence. It encapsulates the views of a child with autism and serves as a reminder that it is important that all professionals must listen and take into account the views of the child.

I AM THE CHILD

I am the child that looks healthy and fine
I was born with 10 fingers and toes
But something is different somewhere in my mind
And what it is nobody knows

I am the child that struggles in school
Though they tell me I'm perfectly smart
They tell me I'm lazy can learn if I try
But I don't seem to know where to start

I am the child that wont wear the clothes
That hurt or bother my feet
I dread sudden noises, can't handle most smells
And tastes there are few things I'll eat

I am the child that can't catch the ball
That runs with an awkward gait
I am the child chosen last for the team
And I cringe as I stand there and wait

I am the child with whom no one will play
The one that gets bullied and teased
I try to fit in, I want to be liked
But nothing I do seems to please

I am the child that tantrums and freaks
Over things that seem petty and trite
You'll never know how I panic inside
When I'm lost in my anger and fright

I am the child that fidgets and squirms
Though I'm told to sit still and be good
Do you think that I choose to be out of control
Dont you know that I would if I could

I am the child with the broken heart
Though I act like I don't really care
Perhaps there's a reason God made me this way
Some message he sent me to share

For I am the child that needs to be loved
And accepted and valued too
For I am the child that is misunderstood
I am different but I look just like you.

Anon – Website chat room

7.2 Family Views and Experiences of Parents and Carers

Members were very impressed by the professionals involved in this review, but more impressed by parents who had by necessity become experts in the field. The parental contribution to this review was overwhelming. A substantial part of the evidence base was provided in written format, and then supported by oral evidence and organised field trips. The key messages from parents and carers were consistent and focused on diagnosis, assessment, advice help and support, health and educational provision and gaps in access to social care services including respite and leisure activities.

The following case studies provided by Solihull families have been selected to **illustrate the points that parents want to be recognised and addressed** as a consequence of this review. It is therefore stressed that these case studies represent individual parent's views and are not therefore necessarily representative of all parents. Equally, the individual case studies are not balanced by the professional perspective so should be read in that context.

Diagnosis

Case Study 1:

A parent described her experience of the diagnostic process in 2003 when her child was referred to the Meadow Centre. The parents report that following the assessment

“despite the fact that we had no experience of children with ASD we were given the diagnosis of ASD “out of the blue”, asked if we agreed and then as we felt at the time, pushed out of the door with a folder in our hands that would ‘explain it all. There was no follow up, no one to turn to and no one to ask.”

The parent recommends that for a parent who has no knowledge of the system and how it works, there should be a fool proof way of ensuring that help is given as soon as possible exactly in the areas where it is needed.

Finding: Many parents referred to their experiences of ‘breaking the news’ and pleaded that this is done with sensitivity and backed up with ongoing emotional and physical support. Parents do not only want to be told what the diagnosis is, but want to know what they need to do about it and who to contact for advice, support and signposting to services. They are also clear that they want advice on educational provision from an educationalist.

Case Study 2:

A parent presented her experience from diagnosis to admission to school:

The child had been supported at the Meadow Centre from 18 months old and she had been overwhelmed with support. However following a diagnosis of ASD in 2005, the support stopped on the grounds that support is not provided post diagnosis. The child was then 3½ years old. She described severe behaviour problems within the home and explained that her son also suffered from a severe bowel condition and was awaiting an operation to allow him to be tube fed. He also suffered from nocturnal enuresis and epilepsy. Sleep deprivation was a major issue and so she had turned to her GP, who offered her valium and a referral to a psychiatrist.

Finding: Many parents cited examples of home based issues that they were struggling to deal with. Behaviour management was high on the list; they highlighted the need to provide training for parents, home-based support and respite/ short-break opportunities. More importantly, they argued the need for professionals to believe them when they say that behaviour at home is difficult even though it is manageable in school.

Case Study 3:

A parent wrote: *“The Meadow Centre was our saving grace it changed our life for good and we are a happier and calmer family knowing how to deal with our son and his needs. But at the time we thought differently we were a family falling apart. The team there were so kind and helpful and always willing to listen. He had assessments at home, school and in clinic, and they were always at the end of the ‘phone if we ever had a problem. After we had finished at the Meadow Centre we were quite glad to have our lives back. It was not until a few months down the line that we realised that the shake of the hand and the pat on the back and all the good wishes of the staff is just where the Borough services finish with autistic people and their families, there are no back up services which we need”.*

Finding: Many parents stressed the feeling of isolation when they are ‘discharged’ from the Meadow Centre. They have built up relationships with professionals that they trust and miss that ongoing support. They feel that they need a care pathway that supports the whole family in an holistic way post diagnosis.

Case Study 4:

A lone mother of two children with autism described how she had set up a support group for parents to fill a gap in local provision. She explained that parents were now being referred directly to her for support post-diagnosis by the Meadow Centre on the basis that there was no professional referral route. She felt that she had no option but to help, but that it was entirely inappropriate to use a voluntary group to fill a gap in provision, especially when the group already had a lot to deal with on a personal level in terms of managing their own challenges.

She also challenged the equality of a system that she felt allocated support on the basis of a parent's ability to 'cope' and cited direct payments as an example.

Finding: It is clear that for a range of reasons, families vary greatly in their resilience and coping strategies. However, it would appear on the balance of the evidence presented that despite the needs of the individual child being equal, services prioritise families under stress when allocating resources, whilst relying on more 'capable' families to not only survive but to support others. Whilst on face value this might seem inequitable from the parental perspective, it is a fact that social policy demands that social care services are targeted towards those families most in need. Resources are allocated on the basis of a carefully and holistic assessment of need that does take individual family circumstances into account

Case Study 5:

A family's experience of a diagnosis 6 years ago:

"What we found was a clear difference between the understanding of those in the education field, and the medical professionals. The diagnosis was slow, but that was understood to some extent. However, any examination or study was invariably stilted and formal. The assessment was particularly clinical with assessors using clipboards and no interaction to study behaviour.....The decision to attend Reynolds Cross was inevitable....From ELA onwards we have always been impressed by the standards, commitment, and dedication of the staff. It is a very special school in more ways than one.....Our only disappointment is the lack of speech therapy availability. Our child communicates to a large extent with the PECS system ...a real concern is the future when s/he leaves Reynolds Cross as an adult.... I think that may well be an important element in the support offered by the Local Authority".

Finding: The post diagnosis period is a critical time for a family. Family's need to connect with an educational professional as quickly as possible following diagnosis to provide reassurance on provision.

Finding: Access to speech and language therapy is limited within the Borough as a consequence of resource limitations

Provision

Case Study 6:

A parent wrote: "My son has Asperger's Syndrome and is presently in a mainstream school waiting for a statement (hopefully). He has struggled throughout and does not fit into mainstream or special school easily because he is bright and socially struggles. There does not appear to be any provision to support his needs. There should be more provision to provide children with 'Asperger Syndrome' to fulfil their academic ability but without the stress of forcing them into a mainstream setting and subjecting them to a school life where they will feel isolated and unhappy"

Finding: Parents of young people with a diagnosis of Asperger Syndrome were the most dissatisfied group in terms of educational provision. They articulated significant concerns about the appropriateness of a mainstream school secondary placement socially and highlighted the inappropriateness of a special school academically. They were concerned that there appeared to be a gap in specialist local provision

Case Study 7:

The parents of a young man with Autism attending an out of authority school argued that the initial stages of diagnosis, assessment and statementing are carried out quite successfullythe problems arise in implementing the statement they recommended that the Borough should develop specialist facilities within the Borough, staffed by young and enthusiastic teachers with a knowledge of autistic teaching methods.

"We think that in view of the steep rise in the number of children being diagnosed with ASD such a school is imperative in the near future, and would certainly save the Borough in the long run. The ultimate aim must surely be to give these children an education sufficient for them to live in the community with minimum support".

Finding: Parents want their child to be educated within the community. Many of them understood the financial arguments for securing local provision and raised questions about the efficient use of resources in terms of the costs associated with supporting external provision

Case Study 8:

A young man received a late diagnosis of Asperger Syndrome and ADHD having carried a variety of EBD labels for over 5 years. He appeared to be managing within a mainstream school but was in fact finding life very difficult. He displayed horrendous moods within the home and became increasingly aggressive. He felt that he couldn't do the work and that teachers did not understand him. He refused to eat, lost weight, refused to attend school became increasingly anxious and refused to come out of his bedroom. He would not allow the curtains to be opened and kept the light on at all times. He displayed psychotic behaviour and self-harmed before being admitted to hospital.

Eventually he underwent a statutory assessment and was admitted to an out of borough specialist school where he is doing very well both socially and academically and now describes himself as feeling 'normal'.

Finding: Young people with Asperger Syndrome are at high risk of suffering severe mental health problems if their needs are not identified and met early. The consequences for the individual and their family are significant and the financial cost to agencies of responding to a crisis is prohibitive.

Relationships

Case Study 9:

A parent wrote "When I consider my own experiences and speak to other parents who have a child with autism, the one overwhelming thing that we would wish to change is the way professionals speak to us, as parents. When your child is diagnosed you have been given some life-changing news. Your life will never be the same again. Your child is not going to grow up and live the life you thought he or she would. Parents need to be spoken to with compassion".

"Give us time to come to terms with the condition, give us support when we ask for it, give us a team we can trust'. Make the journey less traumatic and a 'darn' site shorter".

"Please remember the extended family and support them through this difficult time and remember that they [grandparents] provide valuable support for their family".

Summary

The evidence base has identified that families experience a range of emotions when they are told that their child has an ASD. It is clear that the way that message is provided has a significant impact on their ability to cope. There is a need for professionals to communicate sensitively. Parents want to be spoken to with compassion but be treated as equal partners in the process and be respected as experts in their child's needs.

The individual experiences of families in relation to the services that they received were very mixed. The many case studies provided, exemplified both barriers and creativity from professionals in either enabling or preventing parents from accessing services. Service barriers cited included postcode, access criteria, lack of flexibility, ignorance and professional attitudes.

Positive relationships with professionals that enabled and valued parents were seen as key. Many of the anecdotes presented to the review were attached to individual people who were often cited as indifferent, villains or heroes. The power relationship between parents and professionals was highlighted as a significant issue

Parents were clear that they needed an advocate to support them through the system. They have certain expectations of professional conduct and

“expect professionals to take on board respect and consideration and not to under estimate the impact of things no matter how trivial”.

More positively, parents identified individual champions within most services:

“there are some positive key personalities that do understand.”

Key Points

- There was concern that some parents that are not articulate or do not understand the system will find it very difficult to access services.
- The services and support provided in reaching diagnosis were good, but on diagnosis it is perceived that no specialist support or advice is available to parents, and there is a long waiting list for referrals to the Meadow Centre and speech and language therapy. However, it is acknowledged that the Community Learning Disability Nurse Service does provide specialist advice and support, working in partnership with children, young people and their families.
- The role and importance of the extended family has to be taken into account at every stage, parents pointed out that grandparents grieve too. Consequently there is a need for professionals to include support and advice for the extended family including siblings.

- Parents felt that they needed training to deal with their child's communication, self-help, behaviour, anxieties and social skills. Examples included Makaton signing, PECS, toilet training, eating and de-escalation techniques.
- Some parents had had bad experiences of mainstream nursery and school services, and were concerned about the lack of continuity of learning support staff and the need for these staff to be specially trained.
- There was praise for some specialist units at primary schools, but a feeling that adequate provision was not available at secondary level within Solihull. There is a spectrum of need and therefore a range of education settings are needed to cater for this.
- There were many accolades for special school provision especially the staff at Reynolds Cross School who were seen by parents as experts in the field who truly understood family needs.
- Parents felt that schools need to deploy resources to ensure staff are properly trained.
- It was emphasised that the environment in mainstream schools can be difficult for children with autistic spectrum disorders, it was felt that there is a need for the provision of 'chill out' rooms and quiet areas.
- There were concerns that some schools were using exclusion as a way of dealing with children with special educational needs and that this was usually not appropriate.
- Parents would welcome more help and advice at times of transition, particularly in relation to the transition to secondary school.
- Parents were disappointed that there is no option to assist parents who would like to choose a home based programme such as ABA or Son-Rise Option in preference to school based provision.
- Parents highlighted a potential for the authority to save money in the long run if greater support could be provided at an earlier stage.

Parents Want:

- To be able to access essential support and services without having to fight for it.
- A continuum of support (care pathway) to be put into place to support them post diagnosis from the Meadow Centre (this was a recurring issue).

- Excessive waiting times for assessment and diagnosis to be addressed.
- A general lack of understanding of ASD at whole school level to be addressed “you need to support all of the teachers that deal with these children. It shouldn’t be left to individual teachers to pick up a book when diagnosed”.
- A comprehensive training/ASD awareness programme to be put into place and targeted across the whole range of professionals – this must emphasise the need to recognise the uniqueness of the individual child.
- Schools to address needs and not to use disciplinary processes including exclusion (formal and informal) to respond to behaviour.
- Inequalities within the system, specifically in accessing services within social care to be addressed.
- The lack of specialist educational provision within the Borough to be addressed, particularly in relation to early years and Asperger Syndrome.

Recommendation:

A clear and active partnership needs to be established at a strategic and operational level across health, education and social care, to deliver whole family support including education and care in an integrated approach.

8 Section 2 – Schools and Educational Support Services

8.1 Overview of Provision

All children and young people with SEN *who do not have a Statement* attend their local community school unless their parents have made alternative education otherwise arrangements, by either educating them at home or arranging for them to attend an independent school at parental expense.

The LA does not host any additionally resourced centres specifically aimed at pupils with an ASD. However, the additionally resourced centres at Hatchford Brooke, Bishop Wilson and Widney Schools do successfully accommodate a small number of children with an ASD.

In addition all of Solihull's special schools support children and young people with an ASD. However, it must be recognised that children and young people cannot attend special schools by law, unless they have a Statement of Special Educational Needs.

Solihull is often in the situation of being unable to identify a placement within the Borough for young people with a diagnosis of an ASD. The LA is therefore increasingly seeking placements in special schools maintained by neighbouring authorities. This is usually because the LA is unable to offer an appropriate placement within Solihull's own special school provision. For example, the appropriate special school/s is full, the alternative school is nearer to the child or young person's home, the school cannot offer an appropriate peer group or the level of need exceeds the specialism available.

The majority of pupils attending out of borough provision either have a diagnosis of ASD or are exhibiting severe emotional, social and behavioural difficulties. The LA believes as a matter of policy that out of borough placements usually represent segregated provision that takes children and young people out of their community, and that in many instances such placements do not represent value for money, based on outcomes. It is widely accepted that the fees structure of independent providers too often bear little relationship to the quality of provision.

8.2 Mainstream School Issues

8.2.1 The Curriculum and the Individual

There are many examples of inclusive provision across the Borough in primary, secondary and special school settings. However, the range of skills and understanding within those settings is very variable. Some schools have made extra-ordinary efforts to ensure that all staff have an understanding of ASD and its impact on individual children. They have invested in training for staff at all levels and adapted the curriculum and learning environment to meet need.

However, many more schools find this area of need very challenging especially in the secondary school context. Physical limitations of the school building and environment make structured individualised learning areas difficult to achieve. Equally, children with ASD may require significant people resources to support teaching and learning particularly in the social context. Accessing financial support that is over and above the schools delegated budget can take time as the following case study illustrates.

Case Study 10:

A primary school admitted a child into year 3. S/he came with very little paperwork from the previous school. It was evident even to the 'non-expert' that this child although high-functioning had an ASD. Year 3 was hard work for the child who had a very fixed view of what s/he was interested in and was consequently very hard work for his newly qualified classteacher, who did everything reasonably possible to maintain interest and manage behaviour.

It took time to gather the evidence required for a statutory assessment and for the process to complete. Outside advice was requested, received and acted upon, but by Christmas, the school could no longer cope and a decision to permanently exclude was taken. The child needed an individual curriculum based on and built around their specific interests which the school felt was impossible to achieve within limited resources. It was also clear to all involved that the family needed support too, but this was not forthcoming until the case reached crisis point. The child ended up being placed in a special school maintained by another authority.

Finding: The statutory assessment process is not responsive enough to target responses to high level need before a school placement breaks down. The consequential costs to the child, family school and the LA are often in excess of an early preventative intervention. Failure to target support at both the school and the family leaves a child vulnerable to failure.

Lyndon School shared their response to supporting pupils with an ASD in a secondary context. This demonstrates what a good school can achieve through a carefully planned transition programme supported by appropriate training and targeted support. The school also have a secure view of what could be done to reduce anxiety levels in terms of social interaction and are aware of the needs to support transition into further education, training or employment. This is an example of best practice:

Case Study 11:

Lyndon School reported that:

Current provision:

We currently have 5 students with an ASD. Three have statements with additional support, one is at school action plus and the other student functions well academically but has significant social and communication problems. Integration into year 7 is well planned with the SENCO attending Year 6 reviews at primary school to determine appropriate provision. This might include placement in the small learning support groups organised for year 7.

All staff are alerted to students with ASD either by the SENCO or year 7 coordinator. An after school training session on ASD students and their needs in mainstream schools is held annually. LSAs also work closely with subject teachers to ensure inclusion.

What could make this better:

Funding to run lunchtime clubs for ASD students and their friends to address social and communication difficulties and improve self-esteem – circle of friends.

Additional support when planning work experience such as a list of approved employers who are willing to take students with an ASD and who understand communication difficulties.

Additional support with further education choices to help students and their parents select appropriate college courses with easier access to additional funding for specialist college if applicable.

An alternative secondary school perspective focused on a lack of specialist staff within the school setting who can cater for the autistic learner. They pointed out that whilst schools try to provide a package of support through the deployment of learning support assistants, learning mentors, lunchtime clubs, peer mentoring, links with the LSS, EPS and other agencies in partnership with parents (SNAP) they are finding it very difficult to meet need.

8.2.2 Behaviour and Discipline

It is apparent that some pupils with an ASD who display socially unacceptable behaviour can be misunderstood and their behaviour interpreted as ill-disciplined or anti-social. This is commonly because:

- Pastoral staff such as heads of year may not be included in training sessions and therefore do not know how to deal with ASD behaviour appropriately.
- Hard pressed teachers who have not accessed training will not be able to 'look behind' the behaviour
- Necessary information on individual children and young people may not have been disseminated to key staff

Finding: staff awareness of ASD is critical to a child's success in school. Appropriate training is paramount and will enable staff to respond appropriately, pre-empt difficulties, reduce anxieties, manage behaviour and therefore improve attendance and attainment.

The review identified the following strategies to negate inappropriate responses:

- Treat everyone as an individual whilst appreciating the emotional, social and educational implications of autism
- Ensure school policies take into account the full range of communication needs of children and young people, disciplinary policies are unlikely to be appropriate neither is exclusion
- Provide a personalised flexible curriculum that supports learning style and behaviour with a focus on social skills and the management of feelings
- Provide flexible 'time out' opportunities for pupils needing to 'escape' from their anxieties

In summary, it is felt that if teachers understand the implications of an ASD they are able to support young people more sensitively and appropriately.

However, schools felt that:

“Despite the best efforts of a range of professionals, working in partnership with families, there are some children and young people whose needs are not met by attending a mainstream school, however inclusive, nor by placement in one of the Borough's special schools.”

They felt that there is an unrealistic view of the power of inclusion (mainstream placement) and believe that some specialised provision is crucial

In summary schools want to see:

ASD environmentally friendly schools that offer:

- Individualised learning areas
- A place of refuge in order to take time out from the pressures of the classroom
- Alternative provision for lunchtimes to provide a safe haven or quiet area
- Lunchtime clubs to address social communication difficulties and improve self-esteem, incorporating 'circle of friends'
- Peer mentoring schemes
- Awareness raising for other pupils

Dedicated Additionally Resourced Centre/s

- Establishment of specialist resource centres for pupils to provide educational and therapeutic interventions
- Support for pupils on 'dual placements'

8.3 Special School Issues

Forest Oak, Hazel Oak, Merstone and Reynolds Cross Schools are all well placed to continue to develop their expertise in supporting children with an ASD. It is anticipated that Forest Oak and Merstone will work in partnership to develop a community resource to support children on their roll and within local community schools, following the opening of the new schools building in June 2006.

Hazel Oak and Reynolds Cross are also working together to continue to further develop their well recognised expertise in ASD. Once again, this is all dependent on the availability of continuous training and retention of staff.

Special schools have much to offer in terms of their potential to support mainstream schools and there are already many examples of excellent practice between special schools and primary partners in securing appropriate provision. It is important that the changing profile of young people attending special schools is recognised and that the delegated budgets are sensitive to the increasing complexity of need.

8.4 Support Services

8.4.1 Learning Support Service (LSS)

The LSS offers a range of support to children and young people with a social communication difficulty including those with a diagnosis of ASD. Teachers or support assistants from any of the teams may be involved in supporting the child either in the home, the mainstream class or in a specialist placement.

The LSS also supports some pupils with ASD in its additionally resourced speech and language centres at Hatchford Brook and Bishop Wilson Primary Schools and Alderbrooke Secondary School.

One of the strengths of a multi-disciplinary service is that staff are able to collaborate over the support offered to individual children. Therefore a child with an individual special educational need, such as a visual or hearing impairment, may receive support from staff in the appropriate specialist team who would be able to work in partnership with staff with the specific expertise necessary to meet the needs of a child with an ASD.

The service offers many examples of effective partnership working for example members of the service:

- Are increasingly involved in working with the Meadow Centre towards the early, accurate identification of individual needs
- Have co-operated with colleagues from the EPS and Solihull PCT to provide structured parental support programmes
- Have collaborated with EPS and the Meadow Centre staff in training and advising mainstream school staff
- Work closely with EPS and partners in Solihull PCT to support individuals and help schools develop their inclusive practice
- Have been involved in regional projects (eg developing protocols and training frameworks)
- Have worked with the PCT and special school staff to support pupils in dual placements

However, the service has expressed concern that some mainstream schools, faced with increasing demands to show evidence of raised standards, struggle to address the statutory framework for inclusion and make reasonable adjustments as demanded under the SEN Disability Discrimination Code of Practice for Schools. Examples of practices that particularly affect pupils with ASD include:

- Inadequate or inappropriate differentiation (eg placing high ability pupil in a bottom maths group with an LSA rather than providing challenging tasks and a quiet working area).
- Policies that fail to take account of the full range of communication needs of pupils/students (eg verbal warnings for behaviour rather than visual or multi-sensory communication).
- Poor communication within the school about the needs of individual children (eg no guidance given for lunchtime supervisor to avoid 'overloading' a young pupil with verbal explanation and physical prompts).
- A lack of alternative provision at lunchtimes for vulnerable children and young people (eg no 'safe haven' results in teenagers with Asperger Syndrome becoming involved in conflict with their peers on a daily basis).
- Inadequate provision for personal, social and emotional education within secondary schools (eg students excluded from aspects of the mainstream school).

The LSS have identified the following recommendations to address need:

- A support model that embraces a parental support role for school aged children and young people to provide a much needed link between home and school. Examples of best practice include both Birmingham and Warwickshire's school and family support teams.
- The establishment of specific, specialist resource centres for pupils with significant needs to provide educational and therapeutic interventions plus family services
- The provision of support and respite care for families whose children do not meet the current criteria of the Children's Disability Team
- More effective collaboration with colleagues in the School Improvement, Performance and Partnership Division to challenge and support mainstream schools in developing their inclusive practice.

The LSS feel that it is vital at secondary level that all staff have training in ASD. Difficulties often arise when pastoral support staff such as Heads of Year who can be left out of training deal with an ASD pupil inappropriately. Pupils need access to a place of refuge where they can have time out from pressures of the classroom or they can use at lunch time.

The LSS participates in the multi-agency ASD working group and wholly endorses its philosophy. In particular they are strongly opposed to categorisation of pupils, believing a diagnosis of ASD is a signpost, not a label. The key to providing quality services for young people and their

families is treating everyone as an individual while appreciating the fundamental emotional, social and educational implications of autism. This combination of individual focus and theoretical understanding characterises the effective practice in a range of settings throughout the Borough.

Finding: There is consistent support from parents, schools and the support service to develop a parent support strategy, training for all and specialist educational provision. In addition both parents and the LSS have identified a need to challenge the access criteria for respite care.

8.4.2 Educational Psychology Service

Members of the EPS continue to voice their concern over the emphasis on diagnosis rather than identification of need followed by appropriate intervention.

It is vital that schools, supported by EPs who have involvement over time with pupils and their families, have significant input into the process which moves from identification of need to multi-agency diagnosis. The EPs are also concerned that schools and families can still get different messages from the varied professionals working with them. Better information needs to be jointly developed and shared regarding the process of identification to diagnosis. If this is created in consultation with all key professionals and parent and young people representatives then it would help to ensure a consistent message.

The ring-fencing of EP time would enable:

- Partnership working, leading to increased and more effective input into the Meadow Centre and improved liaison with colleagues from the Learning Support Service
- Support to parents and families at the point of identification of need
- Development work with schools and other agencies across the authority, this would include sharing effective practice in this area. There is a particular gap in terms of information sharing and development work with secondary schools, time is needed to develop this work.

In summary, it is felt that training and development work in this area needs to be better co-ordinated and have a multi-agency input. The EPS have begun to work towards this with one day training for LSAs and teachers of pupils with statements and also through a support group. They have attempted, through the multi-agency ASD group to set up a training sub-group in Solihull to begin this process. It is recommended that the policy framework/guidance which have been researched and created through the West Midlands Regional SEN Partnership in the areas of early intervention and training/development work should be considered and adopted and adapted as appropriate within Solihull.

8.5 Annual Cost of Educational Provision for Solihull Pupils with Statements of SEN for an ASD as at January 2006

The following tables provide a breakdown of the total costs of educating pupils in Solihull who have a Statement of SEN primarily for an ASD

Type of School	Number of Pupils	Allocated Support Hours	Total Cost of Additional Support	Total Cost of Placement Fees	Total Cost of Placements
Solihull maintained mainstream	53	759	£302,841.00	-	£302,841.00
Ordinary Independent	3	41.25	£16,458.75	-	£16,458.75
Independent Special	14	22.5	£8,977.50	£361,109.00	£370,086.50
Maintained Special	29	120	£47,880.00	£319,000.00	£366,880.00
Maintained OLEA* Special	7	-	-	£160,000.00	£160,000.00
Home based programmes	2	-	-	-	£46,000.00
	108	942.75	£376,157.25	£840,109.00	£1,262,266.25
Average cost per placement £11,687					

* OLEA = Other Local Education Authority

A Breakdown of Educational Out of Borough Placements for Solihull Pupils with Statements as at January 2006

	Nos.	As a % nos	Cost	As a % of cost
Autism Spectrum Disorder	12	19.4	323,297	23.9
Asperger Syndrome	2	3.2	37,812	2.8
Emotional, social and behavioural difficulties	32	51.6	681,715	50.3
Moderate learning difficulties	3	4.8	7605.0	0.6
Physical difficulty	2	3.2	24,140	1.8
Speech, language & communication	1	1.6	13,300	1.0
Severe learning difficulty/ ASD	4	6.5	188,329	13.9
Specific learning difficulty	5	8.1	36,238	2.7
Visual Impairment	1	1.6	42,199	3.1
Totals	62	100.0	1,354,635	100.0
Looked After Children (LAC)	19	30.6%	477,544	35.20%

8.6 Alternative Provision - Home Based Programmes

A home based programme is a term used to describe the more unconventional, controversial programmes of intervention that are delivered within the home environment. These include Applied Behavioural Analysis (ABA), Lovaas and Son-Rise Option programmes. Solihull has in total provided financial support for four ABA programmes over the last eight years. Two of these programmes have now ended. One pupil has transferred to an MLD school the other to an Independent Special School that promotes the Higashi system of intervention, at a cost to the Council of £112k per annum. It is anticipated that the remaining two programmes will end with a transition into a Solihull maintained provision.

However, during the course of this review, Members attention was brought to five families who passionately advocated Son-Rise Options as appropriate for their child. The parents of these children made strong representations to Members in the hope of convincing the Council that it was appropriate to offer financial support to implement this programme on the basis that their children were making good progress. Consequently, Members accepted an invitation to see the programme in action within a family home.

Parents estimate the full-time cost of supporting such a programme (40 hours per week, 50 weeks per year) at £23k - £30k per annum.

Members also received evidence from Officers and the Educational Psychology Service that brought into question the validity of the Son-Rise programme, in summary, it was argued that despite the longevity of the programmes existence, there had been no efficacy study to support its claims. It was therefore difficult to make any secure judgement. However, Members were pleased to hear from parents that Lancaster University are due to begin an evaluation of new programmes beginning in the Spring 2006 in the UK and look forward to receiving the findings.

In summary, the debate is clearly complex. Parents appear to want ASD specific provision and in the absence of this turn to alternative interventions that enable them to control their child's education.

The West Midlands Regional Partnership in their report on ASDs took an overall view of intensive home based programmes as follows (English & Essex, Home Based Programmes p10:11)

“Pre-school Programmes – General

Dawson and Osterling (1997) compared the progress of 24 children in eight different approaches and found that nearly all the children were reported to have made significant gains. Although the conclusions are not so meaningful because of the lack of control groups, Dawson and Osterling (cited in Connor,

1998) did identify a useful list of elements which they concluded are essential for a pre-school programme:

P13: Professionals and parents/carers have become bewildered as to which approach should be used with children with an autistic spectrum disorder (ASD). In 1998, the DfEE commissioned a team from the University of Birmingham to “*set out what is known about educational interventions with children with an ASD and to discover what gaps exist in our knowledge*”. Jordan, Jones and Murray looked at interactive approaches, approaches to communication, integration approaches, Division TEACCH, Daily Life Therapy as practised by the Boston Higashi School and behavioural approaches.

Their research concluded, however, that there was *‘no really strong evidence to suggest that one approach for a child with ASD is better than another’* (Jordan, Jones and Murray, 1998).”

On the balance of the evidence available to Members, the Group believe that on this basis it is not appropriate to formulate a fixed view on a clearly controversial issue. However, Members were concerned that families should feel confident in the provision they were being offered and were convinced that early intervention significantly improves the prognosis for progress for a child with an ASD and this is not disputed.

Members noted that the Borough had been successful in implementing the National Autistic Society, Early Bird Programme, which is an eclectic programme that embraces the role of parents and engages them in formal training to enable them to implement a variety of interventions with professional support. This programme had been established through an external funding route that is no-longer available. Consequently, it could be argued that there is a gap in provision for pre-school children with an ASD requiring specialist support within the home.

Recommendation:

That an early intervention programme is re-established in Solihull and that trained inclusion support workers are deployed to continue the support to the families and act as a link with nursery/school staff as the child transfers from home to nursery/school. This role should be developed within a multi-agency context, to ensure that the family have continuity of holistic support in terms of health, social care and educational input.

9 Training and Skills

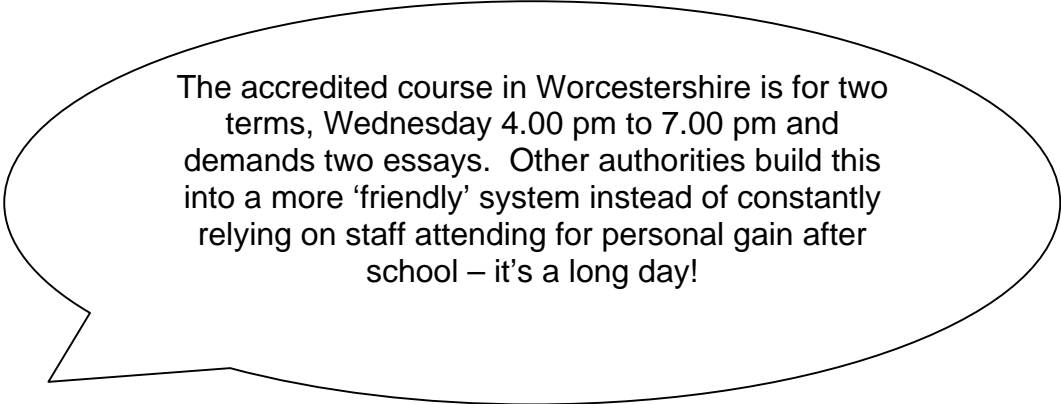
The LA offer formal opportunities for teachers and teaching assistants to access a range of ASD specific training opportunities. However, it was reported that many schools appeared reluctant to take up these courses. It is assumed that this is because it is becoming increasingly difficult to release staff from schools without providing cover. This has become more evident since the introduction of planning, preparation and assessment (PPA) time.

The LA have for the past 8 years offered an accredited course through Worcester College. Some special schools and the LSS have supported staff in completing the Advanced Certificate in Education (ACE), which is a qualification in ASD. All other training is provided in-house. The EPS and LSS run regular training for LSAs and both services provide bespoke autism awareness training at school level on a child specific basis.

The Multi-Agency Group has also developed and disseminated training materials for primary schools and parents. The LA has purchased and disseminated materials produced by the West Midlands SEN Regional Partnership to support ASD awareness in schools.

As a consequence of this review a Teachers Toolkit developed by Warwickshire's ASD Outreach Team, presented as an interactive CD ROM has been purchased for all schools.

However, it is fully acknowledged that ASD represents a continuum of need and there are clear identifiable gaps in training opportunities at all levels including parents, school based staff and support services. ASD is also a disability, so it is essential that service providers have a clear understanding of their duty to make reasonable adjustments under the terms of the DDA to ensure schools are compliant in terms of the provision they make and their policies and procedures. It is also important that training is accessible, for example one teacher wrote:



The accredited course in Worcestershire is for two terms, Wednesday 4.00 pm to 7.00 pm and demands two essays. Other authorities build this into a more 'friendly' system instead of constantly relying on staff attending for personal gain after school – it's a long day!

However, the number of children and young people identified as having an ASD has grown significantly. The impact of training in terms of practice and dissemination within a school setting takes time to establish and is vulnerable to staff changes. Bespoke training should therefore be targeted, needs led and free at the point of delivery.

What needs to be done?

- A training audit should be undertaken and maintained across all services including schools
- An integrated training strategy should be devised
- Training must be delivered through skilled practitioners in a flexible manner ranging from 'bite size' to accredited training
- Existing networks should be developed to enable mainstream schools to gain maximum benefit from sharing examples of effective practice
- Staff should be offered the opportunity to visit to schools and units with specialist provision
- All new staff should be issued with an information pack on ASD
- Training should be made available for teachers within the working week
- Training/development work needs to be better co-ordinated and have multi-agency input.
- Training for parents and carers should be an integral part of the training strategy and ideally be delivered in mixed groups of parents and professionals from across all agencies
- Training should be under-pinned with a support strategy to assist schools in developing their inclusive practice
- Training should not only be ASD specific, but should include communicating with and supporting parents

Recommendation:

An integrated workforce training strategy should be developed as a matter of urgency that encompasses the holistic needs of children/young people, parents/carers and the whole range of professionals working within health, education, social care and any other relevant service.

10 Section 3 – Multi-Agency Perspective

10.1 Multi-Agency Working Group

The Multi-Agency Working Group was set up in Solihull approximately six years ago, by a group of parents and professionals with a specific interest and concern about services and provision for children, young people and their families experiencing an ASD in Solihull.

The group has a broad membership (see appendix (ii)) representing health, social care, education and most importantly families. The group have adopted a work plan that has been based on a National Checklist of Good Practice developed for Local Authorities. The group have prioritised activities against this list and review their progress regularly. The group provided as part of their evidence submission a flavour of their work and included a brief summary of the progress made. They also 'brainstormed' as a group a list of what they perceive needs to be done to ensure that the Authorities can jointly provide adequate services to meet an increasingly broad and challenging range of need within the Borough.

The group confirmed their support of the findings of the West Midlands Regional SEN Partnership's (WMRP) report on Autistic Spectrum Disorders and the Good Practice Guidance issued as a consequence of the All Party Parliamentary Working Group on Autism and formally asked the Task and Finish Group to take them into account. The group commended them because they provided a comprehensive baseline of issues on a national and local basis. The reports proved helpful to this inquiry and were used to inform Members understanding of the regional and national perspective.

The working Group reported that they had recently published guidance for parents and schools on ASD , which had been warmly received. They had also made a major contribution to the compilation of a regional parents pack which was published by the WMRP last year. Members have also made a strong contribution to training, assessment, identification and intervention. For example the Meadow Centre includes a specialist diagnostic team, it is a matter of significant concern that the demand for this service is very high and that they are consequently faced with an unacceptable waiting list. However, the group were pleased to report that this issue has been recognised by the PCT who in response had identified additional resources to enable the team to implement a waiting list strategy.

The Multi-Agency Working Group identified the following issues as areas that need to be addressed:

- Waiting lists for assessment, (a funding/resource and recruitment issue)
- Insufficient personal support for parents post diagnosis
- Provision and support for young people with Asperger Syndrome was identified as a key area of concern

- Insufficient training opportunities for families and professionals
- Significant skill gaps for teaching staff and learning support assistants
- No bespoke service within the learning support service
- Insufficient provision across all agencies
- Access criteria for some services that prevent some families in need from accessing essential support
- Sparse service provision for adolescent needs
- A lack of joint data to enable forward planning
- Access to social care and Learning Disability Nursing Service
- Transition to adult services is problematic.

10.2 Speech and Language Therapy (SALT)

In addition, evidence from SALT suggested that some of the support given to schools and families is duplicated, whilst elsewhere there are gaps. They reinforced the argument that aspects of the 'Early Bird' programme had worked well for some families. The service also wanted to emphasise the families sometimes have unrealistic expectations in respect of what they want to be provided and what will be effective support.

10.3 Child Psychiatry

A Child Psychiatrist emphasised the need to provide an appropriate educational environment for young people with Asperger Syndrome:

“Many of my patients on the autism spectrum who have struggled in mainstream thrive in the protective environment of the Triple Crown Centre. As this is supposed to be a temporary placement only, there is nowhere similar in the Borough for them to graduate to and this places them in a difficult position. The process of getting a statement for their child can be more stressful for parents than actually coping with the child’s behaviour – is there a way in which it could be simplified?”

10.4 Multi-Agency Professional Recommendations - How to move forward and achieve an integrated approach:

- Arrange high quality training for all professionals working with ASD so that everyone can give consistent help and advice to schools and families.
- Create a co-ordinated care pathway of support from referral, diagnosis. Advice through to direct support; using all agencies and professionals with a blurring of professional boundaries.
- Create regular parent education and support groups.
- Develop specialist educational provision for high functioning autistic children in both primary and secondary level, in dedicated units of small size.
- Conduct a comprehensive analysis of provision and training needs, this will enable the development of a more cohesive approach to intervention that recognises that different children have different needs at different points in their life.
- Gather a comprehensive range of professional and parental views.
- Quantify need for specific types of specialist provision through a baseline audit of current provision based on the number and costs of statements of special educational needs for ASD pupils placed outside of the Borough and those whose current provision is not meeting need.
- Develop family centred training, dealing with diagnosis and offering follow up support longer term.
- Identify parent support needs, there is a need for a liaison team/advocacy, key worker.
- Create a helpline/resource centre (ASD specific) for parents and professionals.
- Create a trained 'bank' of learning support assistants.
- Explore effective practice in other Authorities, eg the School and Family Team for Children with ASD and challenging behaviour (Birmingham)
- Audit training, identify gaps and provide as part of a flexible inclusive provision (note: the West Midlands Partnership Training Group is in the process of developing policy and guidelines re: content of training. Also plan to overview training for ASD in the region.
- Develop post 16 education opportunities (in partnership with the LSC) which is local, specialist, non-residential and offers support into work.

10.5 Identification, Assessment and Diagnosis

10.5.1 Prevalence

There is variable practice nationally in the identification, assessment and diagnosis of children and young people with an ASD. It is therefore important that a shared understanding of the definition and a professional confidence in the validity of the assessment and diagnostic process is achieved. A commonly asked and predictable question when conducting any form of research into ASD is how many people have a diagnosis? Data for all manner of reasons is often unreliable.

It has therefore become customary to use the National Autistic Society's (NAS) estimates of prevalence and apply that to the general population.

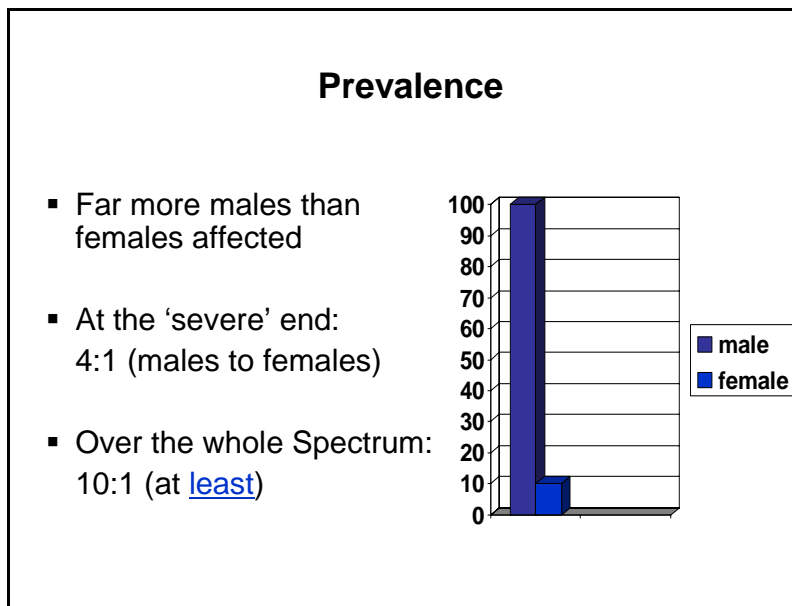
The National Autistic Society Fact Sheet - February 1997, estimates prevalence as follows:

Autism	IQ below 70	20 per 10.000
	IQ above 70	71 per 10,000
Total prevalence		91 per 10,000

Based on these figures Solihull would expect:

- 360-400 children of school age to have an ASD
- 80-90 would have significant learning disabilities
- 280-310 having borderline, average or high ability

The disability has a clear gender bias as illustrated in the following chart:



10.5.2 The Meadow Centre

The Meadow Centre provides accommodation for a range of services. It was created to bring together four existing teams, these included the Children's Disability Team, Learning Disability Nurses and the Autism Diagnostic Team.

The centre receives referrals from all age groups from 2-19 years. It was presumed that the referral figures would reduce over time as older children who were in the system were diagnosed. However, this has not proved to be the case, and older children continue to be referred as and when problems come to light particularly as they reach transition points in their education eg primary to secondary transfer.

The Meadow Centre's 'autism team' was set up with a capacity to handle 40 referrals a year. The number of referrals has, since its inception risen to over 100 referrals a year. When it was established it held 300 case files, it now has over 600. Consequently, professionals report that the time from referral to the completion of an assessment and the sharing of a diagnosis with parents/carers had risen to 12-14 months. However within that, it should be recognised that the team have prioritised referrals for children aged 5 years and under, setting a target of no longer than three months.

At the moment the centre is concentrating on reducing those waiting times to 6 months. Consequently this has meant that energy has been focussed on diagnosis. It has not therefore been possible to provide advice and assistance following a diagnosis and this is openly recognised as one of the biggest concerns raised by parents. This is something that the centre is concerned about and would like to develop in the future.

The team recognise that there is scope to increase joint working with education services and that this would improve the interface for parents. However, the medical and educational processes are very different, for example a formal educational assessment is bound by a statutory process. Health services often require a diagnosis to access services however educational needs are not dependent on a medical diagnosis so provision can be progressed more readily.

Meeting demand within a fixed capacity has become a major barrier to the service's ability to offer a timely comprehensive service for families. The Meadow Centre can therefore only offer an assessment and diagnostic service, it has limited capacity to offer ongoing support for families post diagnosis, although it is acknowledged that the Community Learning Disability Nurse Service do offer support and advice to many children/young people and their families who meet the criteria for service access.

The following case studies were provided as examples of the centres current case-load and serve to illustrate the diversity of needs within this group:

Case Study 12:

This young person is a teenager currently accommodated by the local authority in a placement outside of the Borough at a cost of £4,060 per week.

Prior to being placed in local authority care, s/he was known to the Youth Offending Team and had had numerous court appearances for minor offences. The family reported that s/he had never had real friends and had lately 'got in with a bad crowd' and was very vulnerable to peer group influence. This young person also had learning difficulties and was consequently placed at the Borough's special school for pupils with behavioural difficulties. S/he was permanently excluded, shortly before being diagnosed with an autism spectrum disorder. This young person presents with extremely challenging and oppositional behaviour at times and is very difficult to manage. S/he finds change very difficult and behaviour often deteriorates after a period of significant change. S/he was accommodated in several different placements over a six-month period, because of complex challenging needs

Finding: earlier accurate diagnosis could prevent the use of inappropriate provision and teaching strategies, thus reducing the potential for failure and the consequences of expensive out-of-borough placement costs

Case Study 13:

This child is 4 years old. Mum is a single parent with no additional family support. S/he is severely affected by autism, has no language, challenging and often aggressive behaviour and an extremely poor sleep pattern. S/he has been offered a place at a Borough special school for pupils with severe learning difficulties. Mum is not happy with this offer, as she feels s/he would benefit from being educated in an autism specific environment. Additionally, although the child would be eligible for support through the Learning Disability Nurses, it had not been possible to allocate the case due to staffing shortages.

Finding: The Learning Disability Nursing Team is made up of a group of nurses who work with children and adults who are registered with a Solihull GP, particularly in relation to behaviour. This includes linking with schools and respite care. The team is commissioned by the PCT to work with people who have a learning disability and healthcare need. The team assess, plan, implement and evaluate programmes of care in partnership

with the individual, their families/carers and other professionals. Some of the Healthcare needs include work around: Epilepsy, personal relationships, behaviour, dual diagnosis, continence, smoking cessation, healthy eating, health action, planning and health facilitation.

Some services use the world health organisations definition of learning disability, which is based on an IQ of 70 or below. This restricts access to services for many autistic children. Services include the Learning Disability team (social care) and the Learning Disability Nursing Team.

Case Study 14:

This child is 5 years old. S/he was diagnosed with an ASD in the autumn of 2004. Language and cognitive skills were reported as superficially quite good. However, comprehension was significantly delayed for more abstract concepts. S/he is currently placed in a mainstream school but is suffering from extreme anxiety. Consequently, getting the child into school every morning has become a constant struggle for the main carer. The child has never been reliably toilet trained. S/he is resistant to using a toilet to open his/her bowels and is consequently soiling at school on a daily basis. Because s/he is in a mainstream school and does not have a severe learning disability, the family is not technically eligible for support by the learning disability nursing team. Nevertheless, professionals in recognition of the difficulties faced by parents and the child, have agreed to accept a referral. However, due to staff shortages, there will be a delay before the child can be seen.

Finding: IQ is used as a measure of entitlement to services. However, Autism is a disorder that 'masks' cognitive functioning. IQ scores are not therefore regarded as relevant. Equally, psychologists argue that IQ scores are unreliable and often unhelpful, it is commonly accepted that professionals should identify functional needs and address them

Case Study 15:

This child is 10 years old and has a diagnosis of an ASD. The referral to the ASD team was made by the Child and Adolescent Mental Health Service (CAMHS) team. The CAMHS team had been attempting to work with the child who suffers from extreme anxiety and was presenting as a school refuser. S/he spent some time at the Triple Crown Centre (a pupil referral unit) but found even this protected environment too stressful. After being out of school for some considerable time, s/he is currently being home tutored. The child is relatively bright and does want to learn.

Finding: It is recognised that there is a relatively high rate of suicide amongst young people with Asperger Syndrome nationally, yet this group despite their vulnerability do not have access to disability services.

Case Study 16:

This case study provides a Head Teacher's perspective.

A local infant school had two children on the roll in the Reception class and the school had been allocated a total of 15 hours additional support upon entry. Both children were undergoing formal statutory assessment.

One child, who is severely affected by autism, has little speech and can be very self-directed. The other child has co-morbid ADHD and is extremely challenging to work with because s/he can become very aroused and excited and can at times be impossible to calm down.

One learning support worker left because she was unable to cope. The current support worker does not feel that she will be unable to continue because she does not feel that she has had sufficient training and experience in the area of ASD.

Finding: The lack of expertise within the Borough at operational level, has a significant negative impact on the progress of children with an ASD as well as the staff providing support. This represents an ineffective use of resources

Case Study 17:

This child (a girl) was excluded from Hobs Moat PRU because of challenging behaviour and had been out of full-time education for several months. It had not been possible to find a suitable alternative educational placement. She had become involved with the Criminal Justice System and had been charged with a number of offences. Most of these offences had arisen because of her difficulties in interpreting language, tone of voice and facial expression. She takes everything literally. Her receptive language is several years below her chronological age. She has additional difficulties with memory and concentration. Much time has been spent working with her solicitor to enable him to plead that she should not stand trial in the youth court because of her language and communication difficulties. **This is not an isolated case.**

Finding: Young people with an ASD are vulnerable within the criminal justice system and require strong advocacy support

Case Study 18:

This young person had a late diagnosis of Asperger Syndrome, she had been adopted and has an IQ within the 'normal' range. However, she refuses to acknowledge her disability. She has no natural modesty, extremely poor personal hygiene and is socially and sexually very vulnerable.

Finding: Young people with Asperger Syndrome need specialist support and counselling to come to terms with and understand the implications of their disability. Despite an average or above average IQ, this group of young people are extremely vulnerable in society

Summary:

In terms of diagnosis, the Meadow Centre has been successful in getting additional resources to address the waiting list. However, it is anticipated that the recruitment and retention of highly specialist sought after staff will be an ongoing challenge, specifically in the area of clinical psychology.

Whilst to a degree the waiting list phenomena can be explained, the level of anxiety expressed by parents post diagnosis is a matter of considerable concern. There therefore remains a clear identified gap between assessment and diagnosis at which point intervention appears to slip

Recommendation:

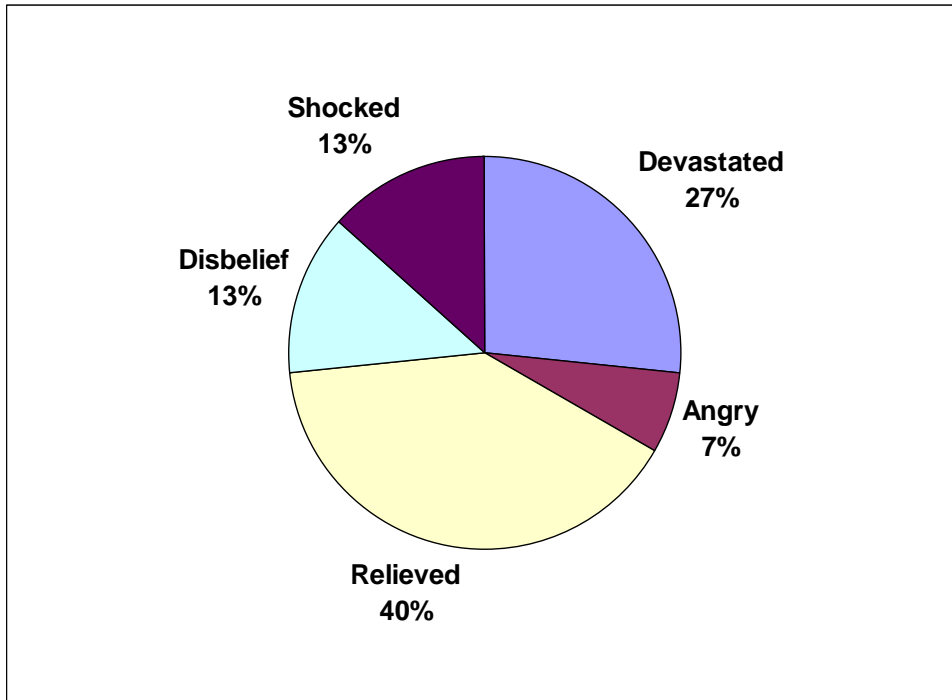
There is an urgent need to develop a continuous care and education pathway for children and families, secured by a parallel continuum of provision. This should be developed through Solihull's Family Support Model and have at its heart a designated lead professional/key worker.

10.5.3 Impact of Diagnosis – What Next?

The parental evidence highlighted the range of emotions parents experience when they are told that their child has an ASD.

This response was thoroughly researched by the West Midlands SEN Regional Partnership through a regional questionnaire sent to parents and carers of children and young people with and ASD. The following diagram illustrates the range of emotions parents reported they experienced:

How Parents Felt Following a Diagnosis



The survey also identified areas of stress for parents as follows:

Three greatest sources of stress for parents of children with an ASD

Primary Source – top of the list	As a percentage
Behaviour management	32.9
Constant care/supervision	12.2
LEA – including schools, service and lack of provision	11.5

Listed in 'top 3'	As a percentage
Behaviour management	51.1
LEAs including schools	61.3

It is therefore essential that parents are supported through the post diagnosis process and that professionals recognise the 'stress' their behaviour can cause to families and take action to minimise this.

The delivery of the diagnosis should be handled with great sensitivity and the impact in terms of an emotional response should be supported emotionally in the first instance and practically in terms of help, advice and intervention.

10.6 Working with Partners

PCT Commissioning

The inquiry received oral evidence from the PCT that explained that the commissioning role for learning disability considers what services need to be planned for and delivered in the future. This is based on known trends in the learning disability population. It is expected that new approaches will be needed to deal with changing trends. An increase in the population of those with learning disabilities has been experienced and it is anticipated that this is likely to increase further. Increased incidence has a direct link with the increase in survival rates of premature babies and the increased life expectancy of those with a learning disability.

However, resources remain finite, despite increasing populations (demand), eligibility criteria for services is therefore becoming tighter. It is felt that there is a need for mainstream services to acknowledge and cater for those with disabilities and that this must be taken into account when developing services. There is a greater need for information sharing between children and adult services particularly in relation to those in residential placements to further improve transition planning.

It is felt that there is a lack of residential provision for children within the Borough. It is also recognised that whilst it is difficult to plan for autistic children it is recognised that early intervention may yield longer term savings, but this is not guaranteed because needs change over time. Consequently, planning ahead is a constant challenge.

Autism West Midlands

Autism West Midlands (AWM) present themselves as an involved independent partner. As an organisation they provide information and a help line on all issues relating to autism. This includes an information service providing fact sheets, details of parent support groups, booklists and various training events. AWM report that they have 55 Solihull members. Family support services include parent training courses which target communication and behavioural strategies. A young person's service aimed at young people with an ASD and Asperger Syndrome is also available to residents in Solihull funded through Children in Need. This service directly targets those young people who have become disengaged from the community.

A criminal justice card produced by AWM in line with the emergency services and criminal justice system is available for young people to carry which explains ASD.

11 National and Regional Perspective

A self-review instrument for individual Authorities

The findings of the West Midlands report indicated that the ASD-friendly Authority should provide the following:

P	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
X	A clear Policy on ASDs that includes training and provision
X	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
X	A range of early intervention measures to support pre-school provision, which are implemented in partnership with parents
X	Training programmes to cover the needs of families and school based staff, which are delivered on a flexible basis
P	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
P	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
P	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
P	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
P	Locally based parent support groups, which receive LEA support
X	A range of ASD-friendly respite/short break facilities
X	All children/young people with an ASD, allocated a key-worker who co-ordinates input from different agencies
X	A policy agreement with the Speech and Language Therapy service, that makes explicit the criteria for clinical priority for intervention

✓ - Met

P - Partially Met

X – Gaps

Authorities across the country have used this 'checklist' to audit and develop their range of services and provision. Solihull has met seven of these key areas, partially met six and is yet to make progress in seven more areas.

These outstanding areas have therefore been absorbed into the key recommendations.

12 Bibliography and References

English A, Essex J (2001) *'Report on Autistic Spectrum Disorders'* West Midlands SEN Regional Partnership

Essex J (2003) *'Solihull's Policy for Special Educational Needs and Inclusion'*

DfES (2001) *'SEN Code of Practice on the Identification and Assessment of Pupils with Special Educational Needs'*.

DRC (2001) *'Disability Discrimination Act 1995 - Part 4 Code of Practice for Schools'*

DfES (2003)

DfES (2004) *'Government's Strategy for SEN, Removing Barriers to Achievement'*

13 Glossary of Terms

ABA	Applied Behavioural Analysis
ARC	Additionally Resourced Centre
ASD	Autism Spectrum Disorder or Autistic Spectrum Disorder
CAMHS	Child and Adolescent Mental Health Service
DDA	Disability Discrimination Act
EPS	Educational Psychology Service
ESBD	Emotional, Social and Behavioural Difficulties
FE	Further Education
LA	Local Authority
LAC	Looked after Children
LSA	Learning Support Assistant
LSS	Learning Support Service
MLD	Moderate Learning Difficulty
NAS	National Autistic Society
OLEA	Other Local Education Authority
PECS	Picture Exchange Communication System
PCT	Primary Care Trust
PRU	Pupil Referral Unit
SALT	Speech and Language Therapy
SEN	Special Educational Needs
SENCO	Special Educational Needs Coordinator
SLD	Severe Learning Difficulty
SMBC	Solihull Metropolitan Borough Council
SNAP	Special Needs Active Partnership
WMRP	West Midlands SEN Regional Partnership

14 Appendices

Appendix (i)

Guidance for Submitting Evidence

A Review of Provision for Children and Young People with an Autistic Spectrum Disorder,

Who is reviewing these services and how?

The Council is conducting a review of the services we offer to children/young people with an Autistic Spectrum Disorder (ASD) and the support available to their families. The Education and Children Overview and Scrutiny Board have appointed a Task and Finish Group to lead the review. The Group is adopting a select committee approach to the review. This means that they are inviting people and organisations with an interest in this issue to provide written evidence, these people are called witnesses. Witnesses include: children, young people and their families; school based staff; support services; health and social services professionals; police and voluntary groups and those who are responsible for delivering Council services. In other words anyone who wants to share with us their experiences and ideas on how to improve our services. The Task and Finish Group are particularly interested in how well professionals work together in partnership to deliver services to families and schools.

How long will the review take?

The Task and Finish Group will complete the evidence-taking stage of the inquiry by the end of July 2005. Councillors are asking that anyone with an interest in this review send their written evidence to the committee by Friday 4th March 2005. It is expected that the report will be available for reply and debate by September 2005.

How will the Task and Finish Group gather its evidence and who from?

The Task and Finish Group has the power to ask for written evidence and documents, to examine witnesses with their consent and to make reports to the Education and Children Overview and Scrutiny Board.

Those who submit written evidence, and others, may be invited to give oral evidence. Oral evidence may be given in public or private. The meeting may be taped or a written record made to summarise the evidence. The time available for taking oral evidence is limited. All witnesses are therefore encouraged to submit written evidence first, even if the group expects to give oral evidence later. This will make meetings, known as hearings, more productive, and ensure that if witnesses are not called to give oral evidence the group still has the benefit of their written views.

The Task and Finish Group will also arrange a series of formal and informal seminars with experts. They will visit people and places to see how things work in practice and how other Council's approach similar problems

What do we want to know?

The areas of inquiry on which we would particularly welcome comments include:

1. Child and young people's views
2. Family experiences
3. Pupil outcomes
4. Identification
5. Multi agency working
6. Intervention and support
7. Training and skills
8. Provision
9. Teaching, learning and the curriculum
10. National and regional perspectives

How do I present my written evidence?

It is helpful to us if your evidence is presented on the official form and sent electronically to jessex@solihull.gov.uk. However, there are no rules on how you submit your evidence. You might want to send an E-mail or write a letter or memorandum. Alternatively, you might want to present a case study, it is entirely up to you.

However you decide to submit your evidence, you should aim to keep it short and concentrate on a few key points. Your written evidence should consist of a brief introduction, any factual information you have to offer and any recommendations for action which you or your organisation would like the group to include in the report. It is important that your evidence is signed and dated with a note of your name and status and you should make it clear whether the evidence is submitted on an individual or corporate basis

How do I present oral evidence?

Oral evidence will be used to supplement what has been said in written evidence. Members will want to explore issues and gain a greater insight into the problems and try out possible solutions. Meetings are therefore likely to consist of question-and-answer sessions and you can be assured that any sensitive issues will be heard in private. Witnesses will be given a clear indication of the possible lines of inquiry before the meeting and members will ensure that you are made to feel welcome and at ease.

Who is on the Task and Finish Group?

Cllr. Ken Hawkins (Chair), Cllr. Graham Craig, Cllr. Norman Davies, Cllr. Dr. Lea, Cllr. Mike Robinson, Mrs. Ann Forder (Parent),

The Lead Officer for the group is Jeannette Essex, Manager Inclusion and Access Services jessex@solihull.gov.uk. Jeannette is supported by Joanne Holmes, Scrutiny Officer, Strategic Services jholmes@solihull.gov.uk. Telephone: enquiries can be made to 0121 704 6039.

We would like to thank you for taking the time to share with us your concerns, experience and ideas for improving our services.

Form For Submission of Written Evidence

In Respect of the SEN Review of Services for Children and Young People Experiencing
an Autistic Spectrum Disorder (ASD) and their Families

Your Name(s) or organisation):	
Contact details:	Address: Telephone: E-mail

This information will be treated in the strictest confidence

I am responding as a:

A parent/carers
Professional:
Other: please Specify

For professionals:

We work for?
My role is?

This response represents:

My personal views and experience
Those of the working group

What key areas of the inquiry are you responding to (please tick those that apply)

1. Child and young people's views	
2. Family experiences	
3. Pupils outcomes	
4. Identification	
5. Multi agency/ partnership working	
6. Intervention and support	
7. Training and skills	
8. Provision	
9. Teaching, learning and the curriculum	
10. National and regional perspective	

Part 1: Your Evidence

What do you want to tell us – you will want to draw upon your experience. You should include examples of what works and what doesn't

Part 2: Your recommendations

Please include any ideas you have for improving the services we offer to children, young people, their families and schools

Part 3: Other Comments

PLEASE RETURN THIS FORM TO: Jeannette Essex, Manager, Inclusion and Access Services: E.mail - jessex:@solihull.gov.uk or post: Solihull MBC, Education and Children's Services, P.O.Box 9 Council House, Solihull West Midlands B91 3QS

Thank you for taking the time to complete this form. The information you have given will be invaluable in helping us to improve the services we offer.

MULTI-AGENCY AUTISM GROUP MEMBERSHIP

- Bernie Adams, SNAP and Parent Representative
- Lynda Akhtar, Team Manager, Children's Disability Team
- Carole Davies, Clinical Leader, Speech and Language Therapy
- Hazel Douglas, Consultant Child Psychiatrist
- Dr Judy Eaton, Meadow Centre, ASD Diagnostic Team
- Jane Edwards, Assistant Education Officer, Inclusion and Access
- Jeannette Essex, Manager, Inclusion and Access Services
- Shirley Heatherington, Manager, Meadow Centre
- Dr Steve Hinder, Consultant Child and Adolescent Psychiatrist, Learning Disability
- Sue Jerrad, Deputy Head Teacher, Hazel Oak Special School
- Noreen Lomasney, Senior School Improvement Adviser, School Improvement, Performance and Partnership Division
- Monica Ludwig, Educational Psychologist and Chair of the Multi-Agency Working Group
- Dr Deidre MacEachern, Community Paediatrician
- Tony Manville, Senior Teacher, Solihull's Learning Support Service Communication and Learning Team
- Liz Reynolds, SNAP