

Autism Spectrum Disorder

Guidance for parents and carers

CONTENTS OF PACK

INTRODUCTION	1
SECTION 1: EXPLAINING MY CHILD'S DIFFICULTIES	
■ What is an Autism Spectrum Disorder?	3
■ What causes ASD?	4
■ Links between Brain and Behaviour	4
■ Diagnosis of ASD	5
■ Associated areas of difficulty	6
■ Further Information	6
SECTION 2: LIVING TOGETHER AT HOME	
■ Support for parents and carers	7
■ Benefits and Financial Support available	7
■ Support with Daily Living	9
■ The Children's Disability Team	9
■ Getting a Break	9
■ Leisure activities	11
■ Managing Behaviour at Home	13
■ Getting Help	16
■ Support for Brothers and Sisters	17
SECTION 3: MY CHILD'S EDUCATION	
■ Does my Child Have Special Educational Needs ?	20
■ A graduated response to children's special educational needs	20
■ Statutory Assessment and Statements of Special Educational Needs	22
■ Making a request for statutory assessment	22
■ LEA agree to carry out a Statutory Assessment	22
■ LEA agree to issue a statement of SEN	22
■ The Annual Review of Statement of SEN	22
■ Educational Provision	23
■ Early Years Settings	23
■ Schools	25
■ Specialist provision within Solihull LEA	26

SECTION 3: MY CHILD'S EDUCATION (continued)

■ Out of Borough Provision	26
■ Where to school?	27
■ Effective ways to help prepare your child for a change of class of provision	28
■ Planning the Transition to Adult Life	29
■ Connexions: Careers and Post 16 Education	29
■ Specialist Colleges	29
■ Work Based Learning	30
■ Adults	30

SECTION 4: DIFFERENT WAYS OF HELPING MY CHILD TO DEVELOP AND LEARN.

■ Key Services Available in Solihull	31
■ Main Approaches and more Specific Strategies	33
■ Main Approaches	33
■ Earlybird Programme	33
■ TEACCH	34
■ Higashi	34
■ Applied Behaviour Analysis (including Lovaas)	35
■ Options	35
■ Specific Strategies	36
■ Circle of Friends	36
■ Picture Exchange Communication System (PECS)	36
■ Musical Interaction Therapy	37
■ Social Stories	37
■ Social Skills Training	37
■ How can I use these ideas at home	38
■ Making Informed Choices	38
■ Questions to ask	39

SECTION 5: GROWING UP-TEENAGE YEARS INTO ADULTHOOD.

■ Developmental Issues: personal, social and health issues	41
■ Some useful approaches	42
■ Valuing People : A New Strategy for Learning Disability in the 21st Century	44
■ Adult Services	45
■ Connexions	45
■ Services for People with Learning Disabilities	46
■ Solihull Action Through Advocacy	47
■ Person Centred Planning	48

SECTION 6: WHO CAN HELP ?

■ Key contacts chart	52
■ An ABC of Professionals, Support Services and the Support they Offer	54
■ Voluntary Organisations	56
■ Local Links	56
■ National Links	57

SECTION 7: RESOURCES

■ Books	60
■ ASD - General	60
■ Teaching and Learning	60
■ Development of Social Skills and Understanding	61
■ Communication	61
■ Support with Family Life	61
■ The Early Years	62
■ Adolescence	63
■ Books for Children and Young People	63
■ Accounts from Adults with a Diagnosis of an ASD	63
■ Special Educational Needs / Learning Disability	64
■ Videos	64
■ Internet sites	66

SECTION 8: FREQUENTLY ASKED QUESTIONS

■ Diagnosis	67
■ Educational Provision	67
■ General	69

Introduction

This information booklet has been written for parents and carers who have a child who has recently received a diagnosis of an Autism Spectrum Disorder (ASD). It aims to provide useful information about Autism Spectrum Disorders, including Aspergers Syndrome, provide information about and signposts to local services including those from health, education, social care and the voluntary sector. It also provides parents with some possible strategies, for example Section 2 includes information about managing behaviour at home and Section 3 includes information about ways to help to prepare your child for a change of class or school. There is a lot of information contained in these pages, it will be impossible to take all of this on board at once but it is there for reference as needed.

The information in this booklet is likely to prompt lots of questions. You might want to make a note of these and discuss them with your contact from the Meadow Centre like the Shared Care Co-ordinator. The Parents Resource Room at The Meadow Centre is periodically staffed by parents or a Solihull SNAP (local Parent Partnership Service, contact details in section 6) representative who might also be available to discuss concerns.

Parents of youngsters with Autism Spectrum Disorders have been strongly involved in creating this information pack, they have informed the content, provided information and have given feedback as the various drafts have been written. SPEAAK (Support Parents for Early Action for Autistic Kids) provided funding for the production of this information pack in conjunction with Health and Social Services.

The pack has been compiled by a working party of parents and professionals from the Solihull

Multi-agency ASD group. The Philosophy statement of this group is as follows:



The voluntary and statutory agencies in partnership with parents and young people within Solihull are committed to the development and delivery of services to children and young people with Autism Spectrum Disorders which will promote:

- Family focussed Services
- Empowerment of children and young people
- Clear access to services and information
- Commitment to multi-agency assessment
- Identification of need
- Early intervention
- Shared multi-agency training
- The most effective use of resources

The information in this booklet is correct at time of publication. Services evolve and therefore information will change over time. This book will be updated. Feedback will be useful to inform these updates. The design of the pack will allow you to add new information as it is updated.

There are currently plans to develop this information as part of a regional information pack for parents.

TERMINOLOGY

Throughout the book the term Autism Spectrum Disorder will be abbreviated to ASD. Autism Spectrum Disorder replaces and is interchangeable with the earlier term Autistic Spectrum Disorder. This term covers a wide range of more specific diagnostic labels as described in section 1.

FORMAT

Information in the pack is presented to enable easy access to key information. Important information is highlighted and symbols used to provide signposts to other services. Thoughts from other parents



The following quotes were contributed by other parents who have a child with an Autism Spectrum Disorder. They reflect a range of experiences and may be useful.

'You are not alone'.

'Enjoy your child, don't let the label override the individuality of your child'.

'Laugh and cry but most of all enjoy your child and let them enjoy you - they are still precious, if not more so'.

'ASD happens in any family, any background - it is not selective'.

'Other people have their own stories, both good and bad. It won't necessarily be the same for you!'

'Take your time, you don't need to read everything at once'

'Try not to project into the future too much - your young child will develop and change, they will not be doing the same things in adolescence and adulthood'.

'It is easy to feel that you are losing control, when the professionals come in it may feel that you are losing choices. Remember it is okay to say you have had enough or are overloaded. You can make choices and express opinions e.g. you can ask to meet professionals at home or at another location!'

'Schools vary enormously'.

'Health visitors are key persons for a young child'.

'If support is there, take it, we've been there, it really does help - even if you are like me and think you don't, there will come a time and when that time comes just pick up the phone'.

'Remember, autistic kids are as different from each other as any other child. They have a core personality first and autism on top. Your child won't necessarily turn in to the text book case in your library book'.

KEY CONSIDERATIONS - ONE PARENT'S VIEWS:

Essential

- Don't overlook other family members. Their needs are also important, especially siblings.
- Look at educational provision - all possibilities and options.
- Collate information, listen and store it e.g. meetings.
- Eliminate hearing and sight problems at an early stage.

Advisable

- Look at available benefits e.g. Disability Living Allowance.
- Take time out for yourself!
- Talk to support groups for both emotional and informative help.

Optional

- Consider different therapies
- Look at respite care, you can always investigate it for the future. Don't feel pressurised to do this though. Respite care can mean as little as one evening a month.

If you would like to speak to or meet with other parents who have children with a similar diagnosis then a good starting point is to contact one of the local groups mentioned in section 6 WHO CAN HELP?: Local Links.

There are several local parent support groups such as SPACE and SOLIHULL SNAP is also a very useful contact.

'You are not alone'.

Section 1: Explaining my Child's difficulties

What is an Autism Spectrum Disorder?

Autism Spectrum Disorder, or ASD, is a term used to describe a group of related developmental disorders. Children with ASD show unusual patterns of development in the following key areas:

- **SOCIAL INTERACTION:** the child has difficulty understanding and relating to other people and does so in limited, unusual and/or inappropriate ways. **Difficulties in getting on with other people range from aloofness and indifference to wanting desperately to make friends but lacking the necessary understanding of social rules and other people's feelings to do so successfully.**
- **COMMUNICATION:** the child may or may not have difficulties in speech and/or language development. However, s/he will have trouble understanding why, when and how to communicate and in interpreting the meaning of other people's communications. This involves spoken language, **gesture, tone of voice** facial expression and body language.
- **FLEXIBILITY OF THOUGHT AND BEHAVIOUR:** this inflexibility can affect play skills, imagination and academic skills. **This may be shown in repetitive activity, a lack of pretend play and imaginative problem solving, obsessive interests and rituals and distress at changes of routine.**

Together, the above three are often known as the "Triad of Impairments" in ASD. The child's problems with social interaction, communication or flexibility may be to any degree, from very severe to really rather subtle and not

immediately obvious in all situations. Hence the concept of a spectrum.

In addition to the "Triad" there is often (but not always) some degree of learning disability or of specific learning difficulty (perhaps in literacy or numeracy). There may also be unusual reactions to sensory experiences (hearing, taste, touch, smell, vision), motor (movement) difficulties and behavioural and/or emotional issues.

The most important thing for you and your child is that his/her particular strengths and needs are identified and understood. The precise label that is used to describe them is far less important, however a wide range of terminology is used and this can be confusing. Below are some of the more specific diagnostic labels that you might encounter. In this pack, the term ASD is used to incorporate all of them:

- **ASPERGER'S SYNDROME:** This is used to describe children on the autistic spectrum who usually have average (or above average) general intellectual ability and who do not have significant speech and language difficulties (though they still have communication difficulties). They often wish to be sociable but find it difficult, and may be quite aware of their "difference" from their peers.
- **ABLE (OR HIGH-FUNCTIONING) AUTISM:** Also used to describe children with good overall intellectual ability. There may be speech and language difficulties as a young child, which could resolve as the child develops. The impairment in social interaction and in particular in sociability is likely to be more severe than in a child with Asperger's Syndrome. However, there is ongoing debate over whether it is useful to distinguish the two concepts.

- **AUTISTIC TENDENCIES, TRAITS OR FEATURES:** This is used to describe a child who has some, but not all of the features of autism.
- **ATYPICAL AUTISM:** This is used to describe a child who shows complex features that may or may not include all the criteria for a clear diagnosis of autism.
- **CLASSIC (OR KANNER'S) AUTISM:** This is used to describe a child with severe difficulty in all three areas of the "Triad or Impairments". Leo Kanner was the person who first described and gave a name to children like this.
- **PERVASIVE DEVELOPMENTAL DISORDER (PDD):** A general term used to describe both autism and other similar conditions.
- **SEMANTIC PRAGMATIC DISORDER (SPD):** Widely used to describe the language difficulties of children at the higher end of the autistic spectrum. It may also be used where it is clear that the main area of difficulty for the child is with language, and the other components of the triad may be less pronounced. There can be confusion about this term as it is used in different ways by different professionals, however there is increasing acceptance that SPD is part of the autistic spectrum. In addition, it is important to note that a child can have semantic (meanings of words and phrases) and pragmatic (knowing what to say, when and how) language difficulties without having SPD (i.e. ASD).
- **SOCIAL COMMUNICATION DIFFICULTIES:** This term is used to describe the types of problems seen in ASD; however not all children with social and communication difficulties will receive a diagnosis of ASD.

Essentially, a child with ASD has ways of perceiving (seeing the world) understanding and interacting with the world that are different from what is typical. This has benefits as well as disadvantages. Each child will have their own strengths and learning styles, for, example a good eye for detail, strong visual memory, or the ability to focus on a specific area of interest and learn a lot about it. Some people with ASD have

exceptional talents, for example in mathematics, music or art. This is not the case for most however, but it is important to acknowledge and build on each child's areas of strength.

What Causes ASD?

ASD is not caused by the way a child is brought up. ASD is not selective - it can happen in any family with any background. We know that it is brought about by physical processes involving the way that the brain functions. What we don't know is exactly how this happens, and it is likely that it happens for different reasons in different children. The vast majority are born with the condition. There are genetic factors involved, which means that family patterns can be seen in the occurrence of ASD and other developmental difficulties. The specific genes involved are not yet known.

Links Between Brain and Behaviour

There is ongoing research that attempts to uncover the types of brain processes that result in the behaviours, strengths and difficulties seen in people with ASD. The following are some of the most prominent theories:

- People with ASD seem to lack (though not necessarily completely) a Theory of Mind (Baron-Cohen, Leslie and Frith, 1985). In other words, they find it difficult to deduce what other people's thoughts and feelings are likely to be in a given situation. This makes it very hard to predict somebody else's actions and leads to problems with making sense of the social world, and of social rules. It also affects communication.
- People with ASD have a particular style of perceiving and thinking about the world. They often seem to lack what is known as Central Coherence (Frith, 1989). This means that they pick up and process information in bits and pieces rather than in terms of the

whole picture, as most of us do. This has pros and cons: a person with ASD may be described as having a very good "eye for detail", but at the same time may have difficulty with integrating different pieces of information and making use of context to aid understanding.

- Most people do not behave randomly. Our brains allow us to plan, organise and monitor what we do; to respond to changes in the environment; to generate new ideas; and to use rules that we have learned flexibly to guide our behaviour. These kinds of processes in the brain are known as Executive Function. People with ASD often have difficulties in this area. This means that their thoughts and behaviour can lack flexibility, they can be disorganised, have motivational difficulties, and struggle to generalise their learning from one situation to another.

All of these ideas have evidence to support them, but none of them provide the full picture and there are many more theories that also have something to add to our understanding of the links between brain and behaviour in ASD.

Diagnosis of ASD

Since Autism Spectrum Disorders are a lifetime condition the process of diagnosis must be careful and thorough. Ideally, diagnosis of ASD should be undertaken by a multi-disciplinary team. It is essential that all aspects of the child and his/her environment be carefully assessed. There should be an opportunity to observe the child's behaviour in a variety of settings (clinic, school, home, for example) and to gather information from the people who know the child well.

Evidence for the "Triad of Impairments" (i.e. in social interaction, communication and flexibility) is the basis for diagnosis of ASD. An important element of the assessment is to see how much each of these difficulties is contributing to the child's overall presentation. It is therefore important to make a complete assessment of the child including his/her personality, his/her

particular strengths and weaknesses, relationships both within the family and in other settings and to assess how much these varying factors impact on his/her autistic spectrum difficulties. It is also important to assess the strengths of the family and of the school environment. As well as assessing the Triad, professionals are likely to enquire about other symptoms sometimes found in people with ASD, including impaired ability to understand the world, sensory and movement difficulties and problems with behaviour and emotions.

An important part of the diagnosis is collecting information about the child's development. This involves detailed questioning regarding the child's social responsiveness, communication skills and behaviour in infancy and early childhood. Early photographs, videos and baby books can be very helpful in this process. In addition, it is vital to carry out direct observation of the child, where careful attention is paid to the quality of the child's social interaction, for example including his/her use of eye contact, appreciation of personal space and desire to communicate with others.

Because there is no specific test which will say whether a child is on the autistic spectrum or not, the process can sometimes seem long and drawn out while the professionals involved are assessing other possible causes of the child's presentation. Sometimes the diagnosis can be very difficult to make, particularly because it can be associated with high levels of anxiety, very poor concentration or behavioural problems which may be causing more of a worry to the family or school at the time.

Diagnosis is only the first step in planning what input would be helpful to the child. A useful diagnosis aims to:

- Describe in detail the child's strengths and difficulties.
- Enable access to appropriate services (and perhaps financial benefits) for the child and family.
- Help parents and carers to access support (for example from voluntary organisations) and to

develop their understanding of ASD and of their child.

- Help the school and/or Local Education Authority in its assessment or the child's education needs and the types of provision and approaches that may be helpful.

Associated Areas of Difficulty

Children with ASD may also have other conditions. Below are some of those most commonly associated with ASD:

- **Anxiety:** Extremely common in children and young people. There may be specific phobias or a general tendency towards anxiety/worry. Changes in routine, difficulty understanding a situation and communication problems often lead to anxiety. Anxiety may be shown via changes in behaviour, sleep pattern or appetite, emotional responses (anger, distress), self-injury, reduced performance at school or other means.
- **Attention Deficit Hyperactivity Disorder/Attention Deficit Disorder:** May also be known as Hyperkinetic Disorder. The child shows extreme levels of inattention, or over activity and impulsivity, or both. There are also difficulties with organisation and social skills.
- **Depression:** Can occur in children and young people with ASD of all levels of ability. Alerting signs include a change in behaviour, apathy, tearfulness, sleep problems, aggression or self-injury. A family history of depression is a risk factor.
- **Disorder of Attention, Motor Co-ordination and Perception:** The child has significant difficulty in these three areas of development.
- **Dyspraxia (Developmental Co-ordination Disorder):** The child has a clear difficulty in the development of motor (movement) co-ordination. For example, s/he may have trouble with dressing (buttons, shoelaces), riding a bicycle, PE, using a pencil and so on. Speech difficulties can be caused by problems with co-ordinating movements of mouth and tongue - this is often known as oral dyspraxia.
- **Epilepsy:** Seizures (fits) occur. They can take many different forms, not all of which are easily recognised. "Grand mal" seizures involve the whole brain and the child loses consciousness. "Petit mal" seizures involve a particular area of the brain and can be simple or complex, depending on which part of the brain is affected.
- **General Learning Difficulties/Learning Disability:** The child's over all development and ability to learn is significantly delayed.
- **Obsessive Compulsive Disorder (OCD):** The child experiences repetitive, unwanted thoughts (for example about death, illness or other negative events) that provoke extreme anxiety. To reduce this anxiety the child feels compelled to perform certain behaviours (for example repeated hand-washing, checking switches etc.)
- **Specific Learning Difficulties:** The child may have problems with reading, writing, maths or other particular aspects of their learning, although their over all intellectual ability is appropriate for their age.
- **Tourette's Syndrome:** There is a pattern of repetitive and involuntary movements or tics (for example eye blinking, lip smacking, shoulder shrugging and so on), vocal utterances (sounds or words, for example throat-clearing, spitting, swearing, shouting and so on) and compulsive behaviours.
- **Vision and Hearing Impairments:** Problems with vision and hearing are often overlooked in ASD. There is a need to be aware of the relatively high rate of problems in these areas, which should be systematically investigated.

Further Information

If you would like more information about ASD in general, diagnosis or any of the associated difficulties described above, you can speak to any of the professionals involved in your child's care. If they cannot answer your queries, they should be able to direct you to somebody who can. Alternatively, you can contact one of the voluntary organisations listed in Section 6. There are also some very helpful books, listed in Section 7.

Section 2: Living together at home

Support for parents/carers

Home life can be full of pleasures and challenges whatever your circumstances. This section provides some basic information that might help to tackle some of the practical difficulties which may occur.

Benefits and Financial Support available

Caring for a child who has a disability can involve extra costs. This section will help you to identify some of the financial support that may be available to you. Levels of benefit change and therefore actual amounts have not been included, it will be important to get the most up-to-date information. If you are unsure about what you are entitled to, or require more information, the following key contacts might be helpful.



Key Contacts:

- Your local DSS Office
- Disability Benefits Helpline on 0345 123456
- Special Needs Officer for Birmingham and Solihull Benefits Agency. This service offers benefits advice and information to parents/guardians of children with special educational needs and is also available to professionals and agencies working with children who fit these criteria. The Special Needs Officer can advise about Disability Living Allowance (DLA), Invalid Care Allowance, Income Support and Incapacity Benefit for Young People (IBY).

Jayne Margets
The Benefits Agency, 224-232 High Street,
Erdington, Birmingham B23 6ST
Tel: 0121 377 4736 Fax: 0121 277 4761
Current Availability: Mondays, Tuesdays and Wednesdays.

Disability Living Allowance (DLA)

A tax-free benefit for people who need help with Personal Care, with getting around, or with both. There are two components to this allowance: **Care** and **Mobility**.

The **Care Component** can be paid from 3 months of age, if your child needs significantly more care than other children of their age. There are 3 rates of payment, depending on the amount of care needed:

- Higher rate if your child requires help day **and** night.
- Middle rate if your child requires help during the day, **or** night:
- Lower rate if your child requires some help during the day, also for over 16 year olds who cannot cook a meal:

The **Mobility Component** can be paid from 3 years of age. Again, there are different rates of payment:

- Higher Rate if your child is unable or virtually unable to walk:
- Lower Rate if your child can walk but needs more guidance or supervision than other children of their age:

Please note that there are other rules for severe mental impairment/behaviour.

Invalid Care Allowance (ICA)

A benefit for people of working age, who cannot work because they are looking after someone who is severely disabled (i.e. receiving DLA Care Component at either the Higher or Middle Rate). You may also be able to claim additions for dependants (children and/or a non-working partner). You are allowed to earn up to **£72** per week (as from April 2001) and still claim ICA.

Income Support (IS)

If your family is in receipt of Income Support, DLA is not counted as Income, i.e. you will continue to receive your full entitlement of IS, plus DLA. In addition, you will also become entitled to a Disabled Child Premium.

Invalid Care Allowance is counted as Income, which means your Income Support entitlement will be reduced by this amount. However it is worth claiming ICA because you will receive a Carers Premium and also you will get Class 1 National Insurance Credits whilst in receipt of ICA.

Working Families Tax Credit is administered by the Inland Revenue rather than the DSS.

If you need help or advice with claiming other benefits, e.g. Child Benefit, One Parent Benefit, Income Support etc, you should contact your local **DSS Office**.

Social Fund Payments

If you are on Income Support, you can apply for a grant or loan to help with essential household items etc that are specific/related to the child's needs. There is a very limited amount of money, so success with application cannot be guaranteed.

The Family Fund (Joseph Rowntree Trust)

This is funded by the Government to help families caring for very severely disabled children under 16. They may give grants for items such as washing machines, holidays, outings, driving lessons, bedding and clothing.



For more information please contact:
The Family Fund
P O Box 50
YORK, YO1 2ZX

Road Tax Exemption

If your child receives the Higher Rate Mobility Component of DLA, you may be able to claim Road Tax Exemption. However, please note that the vehicle is exempt only whilst it is being used solely by or for the purposes of the disabled child.



For more information please contact:
The Disability Living Allowance Unit (VED)
Warbreck House
BLACKPOOL
Lancs. FY2 0UE

When Your Child Reaches 16 he/she may be able to claim other benefits such as Incapacity Benefit (Youth) which is payable for people who are unable to work due to illness or disability, or have been unable to work for at least 28 weeks. Many severely disabled young people will be able to claim this benefit from the age of 16 years, even if they are still at school or college. If you think you are entitled to claim this benefit, contact your local Benefits Office, your local Citizens Advice Bureau or CARA who will advise you on this.

NB: If this benefit is claimed by the young person, child benefit paid to the parent for that young person will cease.

If the young person does not qualify for Incapacity Benefit (Youth) or Income Support, then the Child Benefit continues to be made payable to the carer or parent whilst they are still in education until their 19th birthday.

Support with Daily Living

THE CHILDREN'S DISABILITY TEAM

If your child has a physical, sensory or learning disability, or any condition which substantially affects daily living, the Children's Disability Team can provide:

- specialised information and advice
- help planning for the future
- details of parent support groups and other useful contacts

They may be able to offer:

- advice on managing difficult behaviour
- help with personal care
- short breaks for your child
- sitting services to give you a break
- one-to-one help for your child in a nursery or playgroup
- a place for your child on a playscheme
- financial help with playgroup, nursery or childminding costs.

The Team is made up of social workers and community nurses, who liaise closely with other professionals in the Meadow Centre Team and other professionals too, such as, teachers in Special Units in local schools, etc, to make sure that your child receives the care they need. Your child's needs will be assessed by a member of the Team, and a planned package of appropriate care services offered to meet the needs of your child.



For more information please contact:
The Children's Disability Team
The Meadow Centre
34/36 Faulkner Road
Hobs Meadow
Solihull
B92 8SY
Tel: 0121 722 8010

GETTING A BREAK

You may at some time feel that both you and your child need a break from each other for a few hours, or even over night. There are a range of services available. It would be important to consider which service might best meet the needs of you and your child. Some of these services require an assessment of need and there may be a waiting list, but it is always worth enquiring.

Preschool Playgroups, Day Nurseries, Childminders, Parent and Toddler Groups and Crèches



For information and lists of child care providers please contact:
Solihull Children's Information Service
Tel: 0121 788 4288 or
www.childcarelink.gov.uk

Holiday Playschemes and Out of School Groups



For information and lists of groups please contact Solihull Children's Information Services on:
0121 788 4288 or
www.childcarelink.gov.uk

Childcare Support

Individual support workers are available to enable children with disabilities /Special Educational Needs, up to the age of 11 years, to attend mainstream term time and holiday childcare schemes. An assessment of need is required.




For more information please contact the Early Years Childcare Services on:
0121 788 5380

Family Link Scheme

Designed to offer children with disabilities an opportunity to stay for short periods with another family who have been specially trained and assessed to care for children with disabilities. This can help the child to develop new networks beyond their immediate family.

The scheme offers up to 28 days respite per year to children with a range of disabilities, though the scheme is unable to offer placements to children with severe mobility problems who need non-portable aids and adaptations.

 For more information please contact:
The Children's Disability Team
0121 722 8010

Contact a Family

Contact a Family is the only UK charity providing support and advice to parents whatever the medical condition of their child. They have information on over 1,000 rare syndromes and rare disorders and can put families in touch with each other.

 For more information please contact:
Contact a Family
209-211 City Road
London EC1V 1JN
Tel 020 7608 8700
Fax 020 7608 8701
Minicom 020 7608 8702

Helpline 0808 808 3555 Freephone for parents and families (10am-4pm, Mon-Fri)
e-mail: info@cafamily.org.uk or www.cafamily.org.uk

They can also be contacted locally at:
Somerville House
20-22 Harborne Road
Edgbaston
Birmingham B15 3AA

Speak to Kirsty Mayo
(Regional Information Officer)
or Sarah Chandler
(Regional Development Officer)
on 0121 455 0655

Crossroads

Provides a 'sitting' service for children and young people with disabilities to give parents and the rest of the family a break.

 For more information please contact:
Children's Disability Team
0121 722 8010
Crossroads
0121 733 7295

Lyndon House


Offers specialised health care provision with 24-hour nursing cover for youngsters up to the age of 16 years who have learning disability and an accompanying health care need. An assessment of need is required, carried out by a community nurse.

Lyndon House is located in Olton, Solihull and referrals are made via the community nursing team.

 For more information please contact:
Children's Disability Team
Tel 0121 704 8010 / 722 8010
Oliver House
Tel 0121 799 5860
Lyndon House
Tel 0121 742 5897

Ivy Lodge

Offers short breaks to youngsters age 16+ with learning disabilities and health needs

 For more information please contact:
Tel 0121 779 5654

LEISURE ACTIVITIES

In order to develop and extend your child's interests and meet other children beyond the immediate family you might want to consider making enquiries about local leisure activities. Your child may be able to attend local groups without any additional support, or it may be possible to gain some one to one support.

 For more information please contact:
Solihull Children's Information Services
Tel: 0121 788 4288
www.childcarelink.gov.uk
Or The Children's Disability Team
Tel: 0121 722 8010

When exploring leisure opportunities for your child it is likely to be helpful if you can discuss your child's interests, strengths and needs with the group leader or facility manager.

Solihull SNAP (Special Needs Active Partnership) currently has a Leisure Co-ordinator with a remit to research and develop leisure opportunities for children with additional needs (LOCAN). A database of leisure activities for children with additional needs has been set up on computer, both at the SOLIHULL SNAP office and at libraries in the borough. It will be available on the internet through SOLIHULL SNAP's own website. Details included on each activity will be as follows:

- Nature of activity, age group, disabilities catered for, venue etc
- Name and number of contact person
- Whether the group/provider has experience of particular disabilities or special needs.

 For more information please contact the Leisure Co-ordinator on:
Tel: 0121 788 3699
e-mail: info@solihullSNAP.co.uk


Family outings

Information and examples in this section have been taken from the NAS website with kind permission. The website also provides information about specific attractions such as Alton Towers and Euro Disney.

Being able to go out and about and enjoy the activities that all families enjoy is important for children with autism. It is also important for their brothers and sisters. The following are some ideas about how to plan for activities and also gives details of some of the concessions that are available.


Planning ahead

It is always worth planning a bit ahead and phoning the place you want to visit to find out if there are any concessions and what else is on offer. Some attractions publish special guides for visitors with special needs, which they will normally be happy to send you. Most places are very happy to accommodate special needs and many even go out of their way to offer help and support.

 "James loves music but will always hum along which can disturb people around him. For his birthday I wanted to take him to see the musical Grease which he has watched hundreds of times on video but was worried about how he'd behave. I rang the theatre in advance and explained the situation and they gave us our own box and even gave us our tickets for free!"

Mother of a nine year old with autism

Many tourist attractions will need evidence of a child's disability and their care needs before they will offer concessions. This is particularly true for children with autism who may have near invisible needs. The best person to ask to provide this evidence is probably your GP, failing that a letter from a social worker or evidence that you receive Disability Living Allowance may be enough.

 "Johnny gets really over-excited and tends to tire very easily. Now if we go out for the day I plan what we will do well including breaks well in advance. Often I order a guidebook or something before we actually visit a place. Then before we go Johnny and I draw up a timetable together which we take with us. He paces himself a lot better if he knows what to expect later in the day."

Father of a 10 year old with autism

Eating out

If eating out is a problem bear in mind that many big chains of restaurants have policies on providing for people with special diets. You can generally get details of these policies by phoning your local branch. For example, most branches of MacDonalds will serve an extra burger as a substitute for a bun. Most chains should be able to provide you with details of the ingredients of their products so you can check they are appropriate.



"We practically didn't go out again after Rohan had the mother of all tantrums at the local cinema. He'd been before and knew what to expect but the only seats available when we arrived were at the front which was just too noisy for him. It was only when a friend of the family offered to come out with us for the day that I got my confidence back. Rohan didn't behave perfectly but at least there was another adult there to deal with things when they went wrong."

Mother of a 10 year old with Asperger syndrome

National Key Scheme

If you are planning a day out with your child, accessible toilets may be an issue, especially if your child is likely to need assistance from a member of the opposite sex. Disabled toilets are one solution but many of these are part of something called the National Key Scheme and can only be used by people with a Radar key. Although this scheme can be frustrating if you don't have a key it does ensure that disabled facilities are maintained to high standard and can't be abused by non-disabled members of the public.



For information contact:
 RADAR
 12 City Forum
 250 City Road
 London EC1V 8AF
 Tel: 020 7250 3222
 Fax: 020 7250 0212
 Minicom: 020 7250 4119
 E-mail: radar@radar.org.uk



"Last summer we took the kids to a pick your own fruit farm which all of them loved. It seemed really safe so we just let the older two wander around and eat themselves silly. There was a playground which they spent a lot of time in too. Olly wasn't so keen to go off with the others so he stayed with us picking fruit. We made jam with some of the fruit and he was so chuffed with these jars of jam which he'd practically made from scratch."

Mother of an 8 year old with Asperger syndrome

Information cards on Autism and Asperger Syndrome

The National Autistic Society produces business sized cards, available in packs of 50, that provide brief information and aim to help parents, carers, people with autism and brothers and sisters deal with the public e.g. by handing a card to someone to help explain particular difficulties related to Autism or Asperger Syndrome.



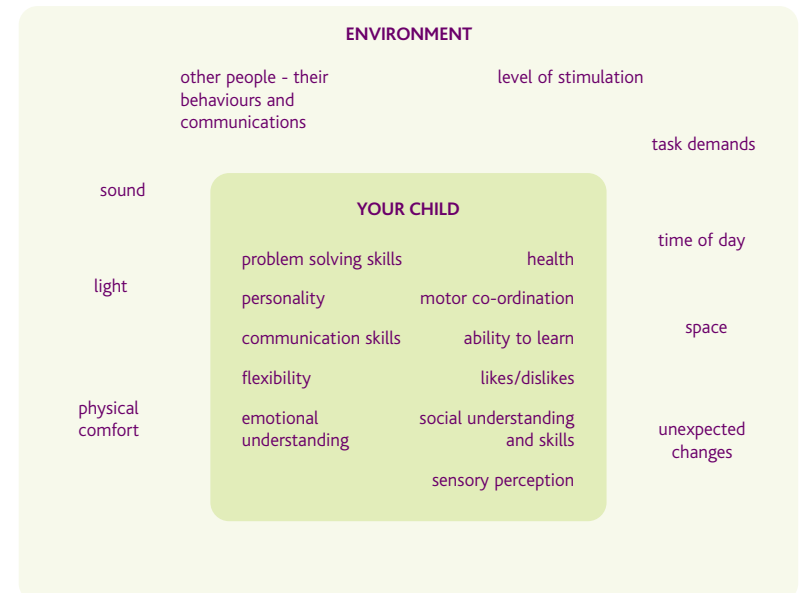
For more information please contact the NAS on:
 Tel: 0207 833 2299
 email: nas@nas.org.uk
 www.nas.org.uk

MANAGING BEHAVIOUR AT HOME

Parenting is always a challenge. However, a child with ASD brings special challenges, often in the form of behaviour that is difficult to understand and to live with. Examples include under developed self-help skills (hygiene, toileting, eating etc.); limited ability to occupy him/herself; ritualistic or obsessive behaviours; over-activity; tantrums; aggression; sleep difficulties; socially inappropriate behaviour and so on. Such behaviours can be the source of considerable stress within the family, and when under stress it can be even more difficult to step back from the situation and think what to do. The aim of the following is to give some pointers for ways of approaching the challenge.

Understanding Behaviour

All behaviour is communication, i.e. it has meaning. It occurs within the context of a particular individual and their environment. You can use what you know about a child and what you notice about the environment in which a behaviour occurs as clues about the meaning of the behaviour. In other words, you begin to understand the behaviour from the child's point of view.



Looking at the gap between your child's skills, abilities and needs and the demands of the environment

With these factors in mind you can begin to ask yourself some questions about what this behaviour might be communicating, for example:

- Is there something that the child does not understand? For example, does s/he understand why s/he is being asked to do something, or even what s/he is being asked to do?
- Are other people in the environment communicating or responding in a way that is unhelpful to the child?
- Does the environment demand a skill that the child does not have?
- Are the sensory experiences in that environment overwhelming for the child?

- Is the child being over or under stimulated?
- Is there something in the environment that might be a particular source of fear, anxiety or another strong emotion for that particular child?
- Is the child communicating a strong like or dislike?
- Is this an unusual response that might be related to the child feeling tired, unwell, uncomfortable etc.?

Zarkowska & Clements (1994)* provide a useful tool that can help explore the meaning of a particular behaviour. Whenever it occurs, they suggest you make a note of the following, known as the STAR approach:

Settings	Triggers	Actions	Results
This includes factors related to the child and his/her environment	What happened immediately before the behaviour?	How exactly did the child behave?	What was the effect of the behaviour for the child?

Settings	Triggers	Actions	Results
Jim does not like changes in his planned routines, when at home he is used to his family and regular visitors but does not respond well when there is an unexpected visitor.	There is a knock on the door.	Jim starts shouting out from wherever he is in the house, telling the person to go away, and pacing up and down.	Unexpected visitors do not stay long ! Jim stops shouting and pacing when they have gone.

Deciding whether to act

Some unusual behaviours are simply part of who the child is and, so long as they do not have too much of a negative impact on family, friendships, learning etc. it may be most helpful (and least stressful to all) just to accept them.

trying a 'wait and see' approach - this can also reveal useful information about when and where certain behaviours are most likely and what they may mean.

A child's behaviour patterns will change as s/he develops and will also wax and wane according to how s/he feels, the environment s/he is in and so on. Unless there is an obvious and immediate need to take some action, it is always worth

In short, therefore, it is worth thinking about whether addressing any particular behaviour is really a priority for your child and your family; also, whether your expectations of the child are reasonable in terms of their strengths and difficulties.

Where to start

Once you have decided that you need to take some action to help your child change a particular pattern of behaviour, there are some simple principles that it is worth bearing in mind:

- Try to focus on one thing at a time. Attempts to solve many difficulties at once are usually overwhelming and stressful for all concerned (especially the child). Gradual change is most effective and least traumatic.
- It may well be that you need to try more than one approach before you find one that really helps. However, do bear in mind that your child will need time to adjust to anything new, so don't give up on any one idea too quickly.
- Use your understanding of what the behaviour means to be clear about what your goal is. Are you aiming to replace an unhelpful behaviour with a new skill; to limit it to certain times/places; to help your child understand a situation differently so that she no longer relies on an unhelpful behaviour? This will help you think about strategies to try. It is seldom useful to have the goal of just eliminating any behaviour. For example, a behaviour that seems odd (spinning, flapping, repetitive activities for example) may in fact serve a very important purpose for the child, for example it may be a source of relaxation or enjoyment, or a way of managing over or under stimulation. In that case, you may want to consider limiting when and where the behaviour is allowed, or altering the environment so that the child does not need it, rather than trying to stop it happening altogether.

When planning what to do, you can again use the STAR model to decide where changes could best be made:

Settings: can the environment be changed so that triggers do not occur? Examples of changes to settings include:

- Preparing the child for changes in routine
- Adapting communication to ensure that the child understands (for example by using visual cues or by simplifying language)
- Altering the sensory environment - noise, light etc.
- Using tools such as Social Stories (See Section 4) to help the child understand a particular situation.

Triggers: Altering settings may prevent triggers from occurring, but this will not always be possible, so any other approaches are based on helping the child to respond to a trigger in a different way.

Actions: Can the child be taught a new way of behaving in response to a particular trigger? For example:

- Developing communication skills
- Teaching a new self-care or social skill
- Providing a safe 'escape route'

Results: Can the effect that the behaviour has for the child be altered? This works in two ways:

- Encouraging the use of an appropriate behaviour by making sure that it has a positive outcome for the child, i.e. by rewarding it for example by using the child's special interest
- Discouraging the use of an inappropriate behaviour by making sure that it does not meet with a desired outcome. This type of negative approach should only be used together with the more positive approaches described above.

Settings	Triggers	Actions	Results
Jim has a visual timetable to help him to predict routines and be ready to finish and change activity. A symbol for an unexpected visitor is added to the timetable.	When there is a knock on the door Jim is shown the symbol and is given a 'special toy' to play with. .	Jim enjoys playing with the toy and this acts as a distraction. Jim learns to tolerate the change in routine, since he develops a new routine for coping with unexpected visitors.	Visitor stay longer. Jim gets lots of praise and positive attention for occupying himself purposefully. Jim gets lots more practice at coping with this situation.

Getting Help

It is not possible here to give a "recipe book" of possible solutions for particular problems, but you can find more detailed information in many of the books listed in Section 7. You can also seek support from other parents (perhaps via SOLIHULL SNAP or SPACE see section 6 for contacts) and from professionals. Your Health Visitor is trained to offer support and advice regarding the behaviour of a young child - you can ask them about the Solihull Approach. If the Early Years Team, other part of the Learning Support Service or Educational Psychology Service is involved, they may be able to help. If necessary, a specific referral can be made to the Child & Family Unit and Child Psychology Service (One Point of Referral) or to the Children's Disability Team (at the Meadow Centre) - any of the professionals involved in your child's care or education can help you to decide whether this would be helpful.

Support for Brothers and Sisters

How do we explain a brother or sister's difficulties?

This will obviously depend on the age of the child. However, it can be helpful for them to understand something about what the diagnosis means in terms of things that their brother or sister finds difficult. There is no right or wrong way to do this, it depends on what feels right for the family. There are books that have been written especially for siblings. They describe the characteristics of ASD and encourage the child to think about their sibling's particular strengths and difficulties. They also explore some of the things that can be difficult and those that can be special about living with someone who has ASD. It is important that the child has the opportunity to ask questions and to express their worries.

What helps?

If siblings of children with ASD know a bit about the condition and its implications, it will be easier for them to understand why sometimes their brother or sister seems to "get away with" things that they would not. It helps to try and set aside regular periods of time when the sibling(s) get undivided attention; also to make sure that they have certain "privileges" themselves. Privacy is important, so the other child (or children) needs to have their own, protected space if at all possible. They can be encouraged to become involved in activities or clubs that will give them the opportunity to be with other children, especially if it is difficult for them to bring friends home.

The Crossroads Young Carers Project aims to support children and young people who may have a caring role within their family, or who may be feeling unhappy or resentful because of the attention which is given to the special needs of someone else in the family. Practical support can be offered such as; signposts to existing services in the borough, individual or group support, advocacy or a range of social activities and outings or holidays.



For more information please contact:
 Tel: 0121 745 8605.
 SOLIHULL SNAP are also an excellent source of information.

Reference

* Zarkowska, E. & Clements, J. (1994). Problem Behaviour and People with Severe Learning Disabilities. London: Chapman & Hall

Section 3: My child's education

As a parent of a child who has recently been diagnosed as having an Autism Spectrum Disorder you may be thinking about how pre-school or school may best meet their needs.

Children and young people with an Autism Spectrum Disorder have a wide range of educational strengths and needs. The aim in Solihull is to provide a range of provision to meet those needs. We have children and young people with an Autism Spectrum Disorder in all of the following types of settings:

- Mainstream Early Years settings, Primary and Secondary Schools, Private, voluntary and independent providers of Early Years Education (with and without individualised support)
- Early Learning Assessment Unit (ELAU) in Solihull
- Additionally Resourced Schools (offering specialist support in the mainstream school, e.g. Language Resource Base in a Mainstream Solihull School)
- Schools catering for children with Moderate Learning Difficulties (MLD)
- School catering for children with Severe Learning Difficulties (SLD);
- Specialist Schools (Outside of Solihull).

Deciding on the best pre-school or school for your child is not easy. Many children cope well in a mainstream setting with varying degrees of support. For others the decision is not so clear-cut. The choice depends largely on your child's individual educational needs, which are determined by their developmental abilities, learning styles, reasoning skills and particular features associated with their Autism Spectrum Disorder. It will also depend upon the skills and knowledge of the staff. Some children with an Autism Spectrum Disorder have needs which will best be met in a special school for children with Moderate or Severe Learning Difficulties. Often at the pre-school stage it is difficult to be definite about how your child will develop, and it may be more difficult to predict longer-term educational needs.

Does my child have Special Educational Needs?

Children who have a diagnosis of an Autism Spectrum Disorder often, though not always, are considered to have Special Educational Needs. The legal definition of children with 'Special Educational Needs' are those that have learning difficulties or disabilities that make it harder for them to learn than most children of the same age. These children may need extra or different help from that given to other children of the same age.

Five main areas of Special Educational Need are outlined in the Code of Practice:

- Communication and Interaction;
- Cognition and Learning;
- Emotional Social and Behaviour Development;
- Sensory and Physical Difficulties;
- Medical Conditions.

So, difficulties with communication, social interaction and flexibility of thought or behaviour are considered to be 'learning difficulties'. Your child may have varying levels of need in these areas and may have other additional learning difficulties e.g. sensory difficulties.

The diagnostic process is likely to help to clarify your child's current Special Educational Needs. It would therefore be helpful if you share the diagnostic information that you have about your child, with the educational setting that they attend. This will support the school in understanding your child's particular strengths and needs, this in turn will help all those involved in choosing most appropriate ways of working with your child.

Just as a good diagnostic assessment will provide information useful to the school, information from school is also an important aspect taken into consideration during the diagnostic assessment.

A graduated response to children's special educational needs

All education settings and Local Education Authorities have duties to identify, assess and make provision for children's special educational needs. The Government have produced a Special Educational Needs Code of Practice (2001) which provides practical advice for LEAs and educational settings about how to carry out these duties. Key features from the Code of Practice are outlined below, but for more detailed information about this please refer to *DfES Booklet: Special Educational Needs-A Guide for Parents and Carers* or ask the school for information, or speak to other professionals you know. SOLIHULL SNAP is the designated Parent Partnership Service for Solihull and is funded to provide support to parents through trained befrienders. They are a very useful contact for information in this area (see section 6)

All maintained and early years educational settings are supported by the Local Education Authority to provide a graduated response to Special Educational Needs, where needs are identified, support given and progress monitored. This approach recognises that there is a continuum of special educational needs and where necessary, increasing specialist expertise is sought to clarify needs and give advice about support.

All settings have to have a Special Educational Needs policy which outlines the schools response, and a Special Educational Needs Co-ordinator (SENCo), who is responsible for the day to day running of the policy, though the daily work with your child remains the responsibility of their teacher or key worker.

Your child's teacher or key worker will be continually assessing your child's progress, informally through day-to-day observations, they will be:

- Seeing how they respond to classroom tasks
- Monitoring emotional social and behavioural responses

Your teacher/ key worker will try to meet your child's needs using different approaches and materials (known as 'Differentiation'). Feel free to ask the teacher, what they know about your child's needs and share the valuable knowledge that you have about your child.

If your child does not make appropriate progress then you may wish to consider with staff, the need for further support. This is called Early Years Action, in early years settings or School Action in a school.

Early Years Action / School Action

The teacher or key worker will work with yourselves and the SENCo to agree ways to work together to meet your child's needs. Agreed targets will be recorded on an Individual Education Plan (IEP), Other professionals who are already working with your child e.g. Speech and Language Therapist, will be asked for their advice. The plan will outline teaching targets and approaches.

If you do not have a copy of the IEP, then you might want to ask your child's teacher for a copy.

You and your child should be given the opportunity to contribute to reviews of progress, sharing concerns and helping school to set new targets. The following are alternative outcomes of reviews:

Progress	Action
continued progress and targets reached	➔ new targets agreed
continued progress and targets reached	➔ return to monitoring by the teacher
slow progress towards targets	➔ targets made more achievable
continued significant difficulties	➔ seek advice from external services

When other services are involved in this way it is called Early Years Action Plus or School Action Plus.

Early Years Action Plus / School Action Plus

The school takes advice from external services e.g. Learning Support Service, Educational Psychology Service, Health Professionals etc. These services contribute ideas to your child's IEP and may work directly with your child. They might also work with staff to increase their skills and knowledge e.g. whole school training about the Autistic Spectrum

There should be ongoing communication between you, the school, and professionals in education, health and social services, through reviews or network meetings in order to share information, check progress and update your child's IEP

When reviewing your child's educational targets, if your child continues to progress, then new targets may be set, or your child may no longer require this level of support, and return to being monitored in the class by the SENCO and teacher, at School or Early Years Action.

For a visual summary of 'A graduated response to children's special educational needs' see Figure one.

Statutory Assessment and Statements of Special Educational Need

MAKING A REQUEST FOR STATUTORY ASSESSMENT

A very small number of youngsters who are receiving the **Action Plus** support, continue to have significant difficulties. It may be necessary for both the school and parents, to seek advice or further assessment from the school's Educational Psychologist. This will help to decide whether an application should be made to Solihull LEA to carry out a more detailed assessment of your child's educational needs - making a request for **Statutory Assessment of Special Educational Needs**. Although, schools alone and parents alone have a right to make an application for a request for Statutory Assessment, from our experiences, applications have been more successful when school's, parents and professionals from the support services are in agreement, making it a better case for your child.

LEA AGREE TO CARRY OUT A STATUTORY ASSESSMENT

An SEN Officer, with the support of other LEA representatives, from Schools and Support Services decide whether or not to carry out a Statutory Assessment. If Solihull Education Authority consider your child's educational needs cannot be met within the school's available resources or provision, then you will be asked to complete a form to give your views and also to get your child's views, where this is possible. Other professionals (this often does include people that are familiar to your child and you) will be asked to carry out more detailed up-to-date assessments of your child's Special Educational Needs.

After receiving all the assessment reports and evidence the LEA will need to consider your child's needs and the type of approaches and support that would best meet their needs. If the needs and provision can be met by your child's school with additional support or strategies provided by the school and other services, then the LEA will write to you to give you reasons for

not issuing a Statement of Special Educational Needs for your child, on that occasion.

LEA AGREE TO ISSUE A STATEMENT OF SEN

A Statement of SEN will be issued if it is felt that your child has Special Educational Needs that require an increase in resources or modifications to the school curriculum, beyond that which the school can provide i.e. for support staff, specialist teaching, access to specialist provision. This is a legal document that specifies your child's educational needs. It will have information for you and your child, the school and support services about areas of strength and areas of difficulty, which need greatest support. It will also include information about how these areas will be supported and by which approaches. There will be an **Annual Review** of your child's statement.

Children who have a statement of SEN will also have an Individual Education Plan (IEP) which outlines short-term targets and strategies. It remains very important that you contribute your own knowledge of your child to this plan, there might also be a strategy that you are able to try at home. This IEP will be reviewed regularly.

THE ANNUAL REVIEW OF STATEMENT OF SEN

If your child has a statement, then this will be reviewed annually in an **Annual Review** meeting. The aim of this meeting is:

- To review your child's progress towards the objectives specified in the statement and also towards short-term IEP targets.
- To bring together information useful in further planning to meet the objectives, and to set new targets.
- To review the special provision made for your child and consider the continuing appropriateness of the statement

As parents/carers you play a key role in this meeting. Views and information will also be sought from your child in a supported way. Staff and other professionals who know your child will also be asked for information.

Educational Provision

EARLY YEARS SETTINGS

Solihull Early Years Development and Childcare Partnership (EYDCP) has been set up to enhance play, care and early educational experiences of young people in the Borough. It is made up of representatives from a range of services and groups including community groups and parents. EYDCP runs the Children's Information Service this provides parents and carers with a one stop access point to information about Childcare and Early Education provision in Solihull. This includes information on:

- Childminders
- Day nurseries and pre-school playgroups
- Out of School Clubs
- Holiday Schemes
- Parent and toddler groups
- Early education service

It can also give information on:

- Working families' tax credit
- Help for parents of children with special educational needs or disabilities
- A signposting service to guide parents to other services and a 24 hour helpline, with a minicom facility for people with hearing difficulties, which is linked to a National Childcare Website: www.childcarelink.gov.uk



For more information please contact the Children's Information Services on: Tel: 0121 788 4288

There is a wide variety of Early Years settings available within Solihull. These include maintained mainstream and special schools, maintained nursery schools, and non-maintained settings i.e. non-maintained private nurseries, independent schools, registered day-care providers such as pre-schools, playgroups, and accredited child minders.

Every non-maintained Early Years Setting has a SENCo who co-ordinates the Special Educational Needs Policy and ensures that children's Special

Educational Needs are met. Two Early Years Area Inclusion Co-ordinators work with these non-maintained Early Years settings to support and develop good practice within them. In maintained Early Years settings i.e. school nurseries, the school SENCo works with the Nursery staff to ensure that Special Educational Needs are identified and catered for. All settings operate a graduated response to children's special educational needs

Support at Early Years Action/Action Plus

The support from external agencies which is currently available is outlined below:

Early Years Team (Learning Support Service)

This is a team of teachers and Special Support Assistants with experience in working with children with SEN. They work both with parents at home and with a range of children and staff in school nurseries, day nurseries and playgroups. The purpose of their support is to teach and assess your child over a period of time. Referral to this service is usually through other professionals, e.g. Health Visitors, but always with the consent of the parents. You may also refer your child to this service. Your child does not require a diagnosis of ASD to have access to this service. Staff from the Service will make an initial visit to determine the level of advice or support that may be necessary.

The Early Years Team may work with children up to the end of their first term in Reception. Following this, your child may be referred to another member of the Learning Support Service who will continue to monitor their progress.



For more information please contact The Early Years Team on: Tel: 0121 770 6267

The Sessional Worker Support Scheme

Solihull Early Years and Child Care Service run this scheme to support children with Special Educational Needs or disabilities to attend pre-school playgroups and holiday playschemes.

Sessional workers can support children in pre-school playgroup for up to two sessions each week. They work with children aged between 2 years 6 months and 5 years.

They aim to help your child to join in with activities, make choices within the group, assist with toileting if required and ensure they are fully included in the group.

You can access this Service by talking to someone from The Meadow Centre, The Child Development Team, your Health Visitor, the Learning Support Service or your contact in the early years setting.



For more information please contact the Early Years and Child Care Service on:
Tel: 0121 788 5365

Training

The Early Years Team in conjunction with the Educational Psychology Service are currently available to lead whole staff training for early years settings where there is a youngster with a Social Communication Difficulty or Autism Spectrum Disorder. It is not necessary for your child to have already received a diagnosis for this training to become available, though there must be involvement from either the Educational Psychology Service or the Early Years Team.



For more information please contact:
The Early Years Team:
Tel: 0121 770 6267
Educational Psychology Service
Tel: 0121 770 6030

Educational Psychology Service

If there are concerns about the progress which a child is making in an early years setting, and there is involvement from the Early Years Team, then staff may discuss the possibility of involving an Educational Psychologist. An Educational Psychologist will work with you and staff to discuss areas of strength and concern. They may become involved in assessing your child's progress, advising on useful strategies and approaches, offering training to staff and liaising with other professionals. If your child continues to have significant needs then an Educational Psychologist will help to explore the need to request a statutory assessment. If this is agreed by the LEA then an Educational Psychologist will be asked to provide advice for this assessment.

Early Learning Assessment Units

If your child's needs are severe and complex, a place may be offered at one of two nurseries with specialist facilities or Early Learning Assessment Units. These are currently at Merstone School and Reynolds Cross School.

My child does not go to a nursery or playgroup, is there any support available for him/her?

If your child is not currently attending a nursery or playgroup then they may be able to access support from the Early Years Team of the Learning Support Service (0121 770 6267) see the details above. For general information about services available a good contact is the Children's Information Services (0121 788 4288)

SCHOOLS

Your child's local mainstream school has a SENCo who co-ordinates the Special Educational Needs Policy and ensures that children's Special Educational Needs are met. Your child's class teacher and also the school's SENCo would be key points of contact for you. All schools operate a graduated response to children's special educational needs.

Support at School Action / Action Plus

In addition to the support provided by school, the following support might also be available from external agencies at **School Action** or **School Action Plus**:

A **Guidance Pack** is being produced for use by staff in schools. It focuses on the needs of youngsters with Social Communication Difficulties including Autism Spectrum Disorders. It provides lots of information to help staff explore areas of difficulty and match difficulties with useful strategies.

Learning Support Service

The Learning Support Service (L.S.S.) consists of teams of specialist teachers and in some cases Special Support Assistants who advise staff and parents and work with children with a range of Special Educational Needs. Children who have a diagnosis of an Autism Spectrum Disorder might have some input from one of the specialist teachers from the Learning and Communication Difficulties Team. S/he may become involved in assessing your child's progress, advising on useful strategies and approaches, offering training to staff and liaising with other professionals.

If a child has a range of difficulties advice may be sought from other teams e.g.

- Emotional, Social and Behavioural Difficulties
- Multi-sensory impairment
- Visual Impairment.
- Hearing Impairment

Referral to this service is currently through the school's SENCo. Your agreement will always be needed for the L.S.S to become involved. The Learning Support Service uses criteria to prioritise support for those who have greatest need.

The Educational Psychology Service

Every school has a named Educational Psychologist who visits and consults with them on a regular basis. They work with teachers, parents and pupils to help identify and deal with the problems that children might be experiencing with their education and development.

If there are concerns about the progress which your child is making then staff may suggest involvement of the school's Educational Psychologist. Your agreement will always be needed for an Educational Psychologist to become involved. They may become involved in assessing your child's progress, advising on useful strategies and approaches, offering training to staff and liaising with other professionals. If your child continues to have significant needs then an Educational Psychologist will help to explore the need to request a statutory assessment. If the LEA agrees this then an Educational Psychologist will be asked to provide advice for this assessment.

Children with statements in their local schools

Often children with a diagnosis of an ASD have their needs met within a mainstream school. The extra provision identified in their statement will be determined by their particular needs. Provision to meet these needs will include any curricular modifications, teaching methods and techniques, specialist equipment, staffing and grouping arrangements. These might include advice and monitoring by a specialist teacher, advice and monitoring by a speech and language therapist and/or targeted support from a learning support assistant.

SPECIALIST PROVISIONS WITHIN SOLIHULL LEA

There is a range of provision for children within Solihull Education Authority. Access to these specialist settings is through a statement of Special Educational Need. The choice of provision will be determined by your child's particular needs. The provisions are as follows:

Resource Centre / Unit Provision

There are a number of units and resource centres that are attached to mainstream schools, catering for children with a range of difficulties, as follows:

Speech, Language and Communication Difficulties

- Hatchford Brook Junior and Infant School, Olton (5-11 year olds)
- Bishop Wilson CE (Aided) Resourced School, Chelmsley Wood (5 -11 year olds)
- Alderbrook Secondary School, Solihull (has some places for 11-16 year olds with speech and language difficulties)

Moderate Learning Difficulties

- Hatchford Junior and Infant Schools, Chelmsley Wood (5 - 11 years olds)
- Chapel Fields Junior School, Olton (7-11 year olds)
- Alderbrook Secondary School, Solihull (11-16 years olds)

There are also 2 units catering for youngsters with **hearing impairments**, two resource centres for youngsters with **physical disabilities**, a primary school unit for youngsters experiencing **Emotional, Social and Behavioural Difficulties** and 2 units for children with **Specific Learning Difficulties**.

Special Schools

Schools for children with **Moderate Learning Difficulties**

- Forest Oak School, Castle Bromwich (5-16 years)
- Hazel Oak School, Shirley (5-16 years)

Schools for children with **Severe Learning Difficulties**

- Merstone School, Merstone Green (Nursery -19 years)
- Reynolds Cross School, Solihull (Nursery - 19 years)

Both schools also have Early Learning Assessment Units for youngsters with severe and complex difficulties.

A school for youngsters with **Emotional, Social and Behavioural Difficulties**.

- Lanchester School, Castle Bromwich (Secondary School)

Further information and contact details for any of these specialist provisions are available through SOLIHULL SNAP (see section 6)

OUT OF BOROUGH PROVISION

There may be a small minority of children whose needs are so particular that they require access to very specialist resources. In such cases it may be necessary to consider a placement in a school maintained by another local education authority or at a voluntary aided or independent special school. These are generally outside the authority's boundaries and so placement may involve a long journey to school or a residential placement. In exceptional circumstances Education and Social Services may jointly fund a residential place in a specialist setting.

When considering the pros and cons of an Out of Borough placement it may be helpful to consider the following range of questions.

WHERE TO SCHOOL?

If you are concerned about the type of support your child is receiving in their current school or are considering a change of educational placement for your child you may want to consider some of the following questions when talking with or visiting schools.

General positive approaches

- How welcoming is the school?
- Do staff listen to your views and want you to share information?
- How are parents and carers involved and informed?
- Do you see children receiving praise and rewards?
- Are behavioural expectations made explicit?
- What are the systems for evaluating progress and setting new targets?
- Are there opportunities for pupils to spend time with youngsters who do not have ASDs?

ASD friendly

- How much knowledge do key staff have about ASDs.
- How is this knowledge reflected in the way staff interact with children, the curriculum and the systems you see in school?
- How can the particular needs of your child be catered for? You may want to ask about particular approaches used to develop areas of social communication, interaction and imagination and also how sensory sensitivities and anxiety are managed. (See Finding out How I can Help with My Child's Learning and Development in Section 4)
- Do staff use a variety of teaching approaches to cater for different learning styles? Is there good access to, for example, computer assisted learning?
- Is there evidence of the use of visual supports and structure e.g. symbols or visual timetables?

- What are the arrangements for less structured periods e.g. lunch and break times?
- What does the physical and sensory environment of the school feel like to you and how would it impact upon your child?
- What are staff : pupil numbers? What are the class sizes and what is the size of the school?
- What is the nature of and the amount of individual teaching?

Practical considerations

- What are the needs of other youngsters in the school?
- What is the distance from home?
- Are there day and residential places?

A more comprehensive list of useful questions has been produced by **Autism West Midlands** (for contact details see section 6).

Advice can also be sought from SOLIHULL SNAP when you are considering the most suitable educational provision for your child.

The school is not meeting my child's needs.

If you feel your child's needs are not being met or understood by school, or if you feel you are not being listened to, then you may want to make an appointment to see your child's teacher, the Special Educational Needs Co-ordinator, or Head teacher. If you would like some support in discussing your concerns with the school, then you may choose to take a friend or family member. Alternatively, you may seek help or advice from Solihull SNAP (Special Needs Active Partnership), a group of people including volunteer parent-helpers trained and committed to working with parents with children with special needs.

EFFECTIVE WAYS TO HELP PREPARE YOUR CHILD FOR A CHANGE OF SCHOOL OR CLASS.

Most people get anxious from time to time. Children can feel particularly anxious at times of change. They may become anxious, for instance, when changing classes or moving to a new school. Sometimes children find it very difficult to cope with meeting new friends and new teachers, subsequently having feelings of uncertainty or confusion.

Children on the autistic spectrum may be particularly vulnerable during transition/transfers (changes within and between schools) because of the inevitable change of environment and routine. Even the child who appears very settled in his or her current environment can have difficulties with changing schools. A carefully planned programme of transition is crucial.

- The receiving class or school will need full information about the educational and social responses of your child. In the case of transition to secondary school the SENCo is likely to be the key link person.
- Liaison meetings will be needed with you (parents), class teachers and SENCOs from both the present and the new school to discuss:
 - Successful strategies
 - Organisation of the learning environment
 - Possible stress factors in the new class and school environment
 - Strategies to promote personal, social and educational development.
- A programme of visits to the new class or school should be arranged, to introduce your child to the new environment and key members of staff. A visit by key staff from the present school may help your child to become more familiar with them and help them to identify possible sources of stress in the new environment so that contingency plans can be made.
- Your child might find it helpful to have visual reminders such as photos, a plan of the school or a colour coded timetable, to help them to prepare and rehearse for the transition.

- What may appear to be small changes, such as a new school uniform may need to be introduced slowly. Your youngster may need to practise putting the new uniform on e.g. tying a tie.

It will be important to work with your child to understand their expectations and possible anxieties. Specific concerns may be tackled using a 'Social Story', which outlines expectations of a situation and clarifies useful strategies (See Section 4).

- Some effective ways of introducing your child to all the staff of the receiving school might take the form of:
 - a talk by the SENCO from the current school about your child including their strengths and likes, tips about stress triggers and successful ways of working with your child
 - a video of your child at school and at home
 - a 'passport' compiled by your child and an advocate (e.g. parent, teacher, specialist support assistant) which outlines important information that they would like to share with new staff. This might include likes, dislikes, stress triggers and helpful strategies. This 'passport' might provide 'security' for your child in new situations e.g. when there is a supply teacher in the class. The passport might also include relevant 'Social Stories' (See section 4 for a description of these).
 - It may be helpful if a key contact within school is identified, this may be the SENCo, a Year Head or a preferred teacher or LSA.
 - A 'buddy' system, or 'Circle of Friends' is likely to provide further peer support for your child when starting at a new school (See Section 4). Some secondary schools operate 'Peer Mentoring Programmes' where older youngsters are trained to give some support to children joining Year 7. Ask the receiving school about any of these 'buddying' arrangements.

Introductory planning meetings will need to be followed by regular planning and monitoring meetings for the core staff and parents. Meetings may need to be weekly during the initial phase of transition.

Planning the Transition to Adult Life

If your child has a Statement of Special Educational Need then in order to prepare for a smooth move in to adult life, a wider range of professionals will be included in the Annual Review in **Year 9**. The additional part of the Annual Review is called a **Transition Planning Meeting**. People who are likely to be invited to this are:

- Health Professionals
- A representative from Social Services, if your child is disabled.
- A Connexions Personal Adviser.

At this meeting a **Transition Plan** will be devised. Students and parents will be fully involved in writing this plan alongside the other professionals. This plan will outline on - going school provision and post - school arrangements. The Connexions Personal Adviser should co-ordinate the delivery of the plan. You will be given a copy of this plan. It will be up-dated at following Annual Reviews.

CONNEXIONS: CAREERS AND POST 16 EDUCATION

The Connexions Service is being set up in England to ensure the smooth transition from adolescence to adulthood, so that every young person has the best possible start in life. Its aim is to provide all teenagers with the help and support they need to participate in learning and achieve their potential.

Solihull Connexions was launched in September 2002. The Careers and Youth and Community Services have been brought together under the Connexions Banner. Connexions provide Careers Advice, Guidance and Information Services within Solihull Metropolitan Borough to all young people who are between 13 and 19 years of age and for young people who have Learning Difficulties and/or Disabilities between the ages of 19 and 25 (before 25th birthday).

Connexions has Personal Advisers who specialise in offering the following Information, Advice and Guidance:

- Suitable further education courses
- Specialist Colleges
- Work Based Learning
- Employment
- Additional support available

Initial contact is made when the young person is in their last few years at school and the support continues while they are in further education, work based learning or are unemployed.

SPECIALIST COLLEGES

There are a number of Specialist colleges that offer residential placements to young people with Learning Difficulties and Disabilities (including ASD). These placements are usually funded through the Learning & Skills Council, their duration is normally for a maximum of 3 years. The application process is quite lengthy, it is therefore recommended that parents/carers consider starting the process at least one year in advance i.e. Following the Year 9 Annual Review.

There are 2 directories that offer information on each Specialist College

- NATSPEC - National Specialist College Directory
- COPE - Directory of post 16 residential education & training for young people with special needs.

The sort of information contained in these directories includes:

- Contact names, addresses, telephone numbers
- A brief description of each college and the support they offer

These directories should be available in school - if not contact Connexions (formerly Central Careers) on the number below.

WORK BASED LEARNING

Central Careers maintains close links with a number of Training Providers. Additional help and funding are available and Central Careers endeavours to ensure that appropriate support is available with the Training Provider to whom the young person is applying.

ADULTS

Central Careers offers similar information, advice and guidance service to adults but, as Central Careers is a private company it may be that some of these services have a fee attached.



For more information please contact:
Special Educational Needs
Co-ordinator
Connexions - Shirley Office
331-333 Stratford Road
Shirley, Solihull
B90 3BL
Tel: 0121 251 1800
e-mail:
proadknightscott@centralcareers.co.uk

Section 4: Different ways of helping my child to develop and learn

Key services available in Solihull

Most of the help that you and your child receive will be provided by health, education, social care and voluntary organisations locally. These will not necessarily be ASD-specific services and similarly the approaches recommended will not necessarily be labelled as ASD-specific. Rather, they should be tailored to your child's needs. The following are some of the services and professionals you may come into contact with:

General Practitioner (GP)

Your GP is your first point of contact for any concerns about your child's health or development. He or she may be able to offer advice/treatment or can make referrals to other appropriate services.

Health Visitor

A health visitor is a trained nurse who works in the community with families. You have access to support from your health visitor until your child reaches school age. A health visitor can assess your child's development and can also offer advice and support regarding many issues, for example feeding, behavioural difficulties and sleep, as well as general health issues. You can contact your health visitor via your GP surgery.

School Nurse

School nurses are available to see all children of school age. Each school has a named school nurse. School nurses are involved with mental health issues (e.g. behaviour problems, bullying, anxiety, depression) - they may provide support and advice themselves or refer on to an appropriate professional.



The school nurse can be contacted through the school or by telephoning the local Child Health Clinic or by telephoning the School Health Department at Solihull Primary Care Trust (0121 711 7171).

Speech and Language Therapy (SALT) Service

In Solihull, Speech and Language Therapists work with children and families at home, at school or in clinic settings. They may work with children individually or in a group. A therapist will probably be involved in the assessment of your child and may then also provide therapy or a programme of work to be carried out at home or school, though not all children with ASD will require ongoing SALT input. As well as speech and language skills, assessment and therapy is likely to focus on areas such as attention and listening, play and imagination, non-verbal communication, social understanding and skills, and understanding the purpose of communication. A referral to the SALT service may be made by your GP or health visitor, paediatrician, school or other professionals.



For more information please contact:
Speech and Language Therapy
(SALT) Service
20 Union Road
Solihull
Tel: 0121 711 7171 Ext 2234

Child and Adolescent Mental Health Services (CAMHS)

This includes the Child and Family Unit (CFU) and the Child Psychology and Psychotherapy Service. The CFU provides assessment and treatment for children and adolescents aged 1-17 (and their families) who have complex emotional, behavioural and psychiatric difficulties. The service is provided to all children, including those with ASD and other developmental difficulties. The Child Psychology and Psychotherapy Service also caters for young people up to 17 who have complex emotional and behavioural difficulties. It provides short term family work, individual psychotherapy for children, work with parents and behavioural approaches with families. Referrals to both of these services are accepted from most professionals via the 'One Point of Referral (CAMHS)' which is based at the Child and Family Unit.



For more information please contact:
Child and Family Unit
Crabtree Clinic
Chelmsley Wood
Tel: 0121 788 8511

The Meadow Centre

The Child Development Centre, Children's Disability Team and Land Lane Centre for Children with Social and Communication Difficulties have all moved into the Meadow Centre and have been joined by others to create the Meadow Centre Team, which is now a multi-professional team.

The Meadow Centre provides a service for any child or young person in Solihull who is under the age of 18 with complex needs. This may include significant social communication difficulties, a learning disability or profound physical or sensory disability. The aim is to provide early identification and early intervention through a co-ordinated family centred service involving all agencies and voluntary services and in partnership with parents.

There is some input from the following range of professionals within the Meadow Centre.

Administrative Staff
Community Paediatricians
Child Psychiatrists
Child Psychologist
Community Nurses
Educational Psychologist
Health Visitor
Learning Support Service Teacher
Nursery Nurse
Occupational Therapist
Physiotherapist
Social Workers
Speech and Language Therapists
Shared Care Co-ordinator

The team provides assessment for children with difficulties in social communication and/or social understanding; diagnosis of Autism Spectrum Disorder is also provided if appropriate. In addition, advice and support is offered to families and schools, though this is limited by resources. Together with Solihull Local Education Authority, staff from The Meadow Centre operate the EarlyBird Programme, which is an early intervention programme for families of pre-school children with Autism Spectrum Disorder. This Programme is described further below.



For more information please contact:
The Meadow Centre
34/36 Faulkner Road
Hobs Meadow
Solihull B92 8SY
Tel: 0121 722 8010

Educational Provisions and Professionals

A great deal of your child's time is spent within educational settings, and work within these settings provides the best opportunity to support your child's learning and development. Please see section 3 for information on the support provided within the education system.

One of the ASD-specific approaches offered by the Learning Support Service Early Years Team and staff from the Meadow Centre Autism Spectrum Disorder Service, is the EarlyBird Programme, which is an early intervention programme for families of pre-school children with Autism Spectrum Disorder. This is outlined further below.

Voluntary Organisations

There is an excellent network of voluntary and often parent-led groups in Solihull. They can provide support and advice regarding issues at home and school and often provide activities for families. At the Meadow Centre there is a parents resource room This is run by parents and SOLIHULL SNAP. It has lots of information, a computer for searching for further information and details of support for parents, children and young people.

Parent Partnership Service (Solihull SNAP)

Each Local Education Authority must provide a Parent Partnership Service to offer parents and carers accurate, neutral information on their rights, roles and responsibilities within the Special Educational Needs process, and on the range of options that are available for their children's education. Parent Partnership must also provide access to an Independent Parental Supporter for all parents who want one. In Solihull the Parent Partnership Service is run by Solihull SNAP, an independent, voluntary organisation which supports parents and carers of children with special needs.

Solihull SNAP has trained staff and volunteers who can give information and support to parents and carers.

Main specialist approaches and more specific strategies

This section describes some of the approaches that are commonly used to help children and young people with ASD. This is included in the

pack for your information, but the approaches used with your child depend on his/her individual needs, the school s/he attends and your own choices as a family. Not all of these approaches will be available in LEA or private schools, and not all will be funded by the LEA or Health Service. By including these descriptions here we are not promoting or recommending any particular approach or programme. Further information about different approaches and therapies is available through the National Autistic Society (NAS).

SPECIFIC APPROACHES

The Earlybird Programme

This was set up by the National Autistic Society to help parents understand ASD and how it affects their child. It is a registered trademark of the National Autistic Society. The programme is designed for pre-school children and those not in full-time education. It aims to:

1. Support parents in the period between diagnosis and school placement.
2. Inform parents and help them facilitate their child's social communication and appropriate behaviour within the child's natural environment.
3. Help parents in establishing good practice in managing their child at an early age, preventing the development of inappropriate behaviours.

The programme accepts families of pre-school children with a diagnosis of ASD. Groups of six families at a time take part in a 12 week programme involving daytime training sessions for parents interspersed with home visits to help individual families put into practice what they have learned.

This programme is currently being run in Solihull as a joint initiative between the Health and Education services.



For more information please contact:
The Meadow Centre
Tel: 0121 722 8010
Learning Support Service
Early Years Team
Tel: 0121 770 6267

TEACCH (Treatment and Education of Autistic and related Communication Handicapped Children)

This approach emphasises structured teaching based on observations of the child, partnership with parents, and has an emphasis on independence training. Visual methods are used to communicate and to teach, minimising the need for auditory processing skills and recognising the predominantly visual learning style of youngsters on the autistic spectrum.

The approach requires that adaptations must occur in the three major areas of the child's life: home, school and the community. Starting with a comprehensive assessment (identifying what the child knows and what the next areas of learning are) the approach comprises a number of interconnected elements, which are based on structured teaching:

- 1. Physical Structure** - refers to the way the environment is organised. There are clear visual boundaries segmenting the space into recognisable parts. This helps the children understand what they are expected to do in each area. In the area set aside for work, distractions are kept to a minimum (e.g. use of a workstation).
- 2. The schedule** - tells the child visually what activities will occur and in which order. Using objects, photos, pictures, numbers or words (depending on the individual's developmental level) the child is helped to understand a sequence of events.
- 3. Work systems** - enable the child to be taught the following: What task or activity do I have to do? When will I have finished? What will I have to do next?
- 4. Visual clarity** - tasks are presented visually so as to make the expectations clear, highlighting the important information and minimising verbal instruction.

In the UK, TEACCH strategies are used in most specialist schools for children with ASD, and they have also been found to be useful in supporting children in mainstream schools and early years settings. It helps move towards independent working and is suitable for use across the age and ability range.



For more information please contact:
www.teacch.com
<http://www.unc.edu/depts/teacch/>

Higashi (or Daily Life Therapy)

This approach was developed in Higashi School in Tokyo. The curriculum consists of teaching children in group activities which are highly structured and in which child-child imitation is encouraged. Children learn to follow the group activities. There is an emphasis on physical activities and an academic curriculum consisting of movement, music and art. Rigorous, daily group exercise is used to reduce anxiety and build stamina. It helps students to understand rhythm and routine. There is also a strong academic focus and social inclusion is promoted. The approach caters for pupils aged between 3 and 22 years old. A school has recently been established in the UK that follows the principles of Higashi with some adaptations to the UK context.



For more information please contact:
www.ulst.ac.uk/pap/bostonhig.html
This site gives a parent's view, or
www.musashino-higashi.org/english.htm

Applied Behaviour Analysis (ABA), including Lovaas, also known as the Early Intervention Programme (EIP)

Applied Behavioural Analysis is a behavioural approach to teaching new skills and behaviours. It involves analysing a skill and breaking it down into small teachable steps, which form the basis of a teaching programme. Each step is presented as a clear goal and successful performance is rewarded. The Lovaas method is an early intensive intervention approach based upon ABA for children with ASD and other related disorders. It was created by Dr Lovaas at the University College of Los Angeles in the USA. Lovaas' model of ABA is 'Home-based'. Parents are generally involved in the delivery of the programme and are taught to:

- observe their children's behaviour systematically to identify its problems and gaps in skill development
- work one-to-one on these
- measure progress.

This model involves 40 hours one-to-one teaching each week. That is 6-8 hours per day 5-7 days a week for 2 or more years. Teaching sessions last 2-3 hours with breaks. A small group of workers are generally involved in delivering the programme. All skills are broken down into small tasks, which are achievable and taught in a very structured manner (known as "drills") and accompanied by lots of praise and reinforcement.

The intervention programme progresses very gradually from teaching basic self-help and language skills, to teaching non-verbal and verbal imitation skills. The second stage teaches expressive and early abstract language and interactive play with peers. At more advanced stages of the intervention a school integration programme is adopted.



For more information please contact:
PEACH (Parents for the Early Intervention of Autism in Children).
Tel: 01344 882248
Website: www.peach.org.uk or
<http://www.Lovaas.com>

Options (or the Son-Rise Programme)

This programme was developed in the USA. It is based on the idea that the child with ASD finds the world confusing and distressing, and therefore attempts to shut it out. The aim is to make social interactions enjoyable for the child so that, gradually, involvement with people becomes more appealing than engaging in unusual or ritualistic behaviours. Adults working with the child are trained to accept the child's behaviours and, in order to make a connection with the child, to join in with the activities that the child prefers. Other activities can then be introduced slowly. This approach requires intensive one-to-one work with the child, usually carried out by teams of 'therapists' at home in a dedicated 'therapy room'.



For more information please contact:
www.son-rise.org or e-mail
sonrise@option.org

SPECIFIC STRATEGIES

Circle of Friends

Many schools have 'mentor schemes' where older children take new pupils under their wing, show them around and introduce them to classmates. If there are ongoing concerns related to making friends or relating to peers, another more structured approach is called 'Circle of Friends' which is an approach involving classmates that can be used in welcoming or supporting a student with special educational needs. This approach does not see the child as the problem. The child's difficult behaviour is seen as a reciprocal interaction between the child and the social environment: the peer group play a major part in maintaining the problem behaviours. The purpose of the circle is to gather round the child a group of friends who will include him or her in activities in and out of school. The approach aims to:

1. Create a support network for the child, helping them to make friends.
2. Reduce the child's challenging behaviour by giving them a sense of belonging.
3. Raise awareness among classmates and use pupil culture to develop empathy and understanding about why the child is behaving in an inappropriate way and how best to identify choices, subsequently increasing the child's understanding of their own behaviour and giving them more choices.

Setting up a 'Circle of Friends' requires that parents/carers give permission for and are supportive of the approach; staff commitment and sufficient time to run the Circle of Friends meetings, and more importantly that the child accepts this approach being taken. Members of the Educational Psychology Service or Learning Support Service are often involved in setting up 'Circle of Friends'.



For more information please contact: Your school SENCo, who may be able to discuss this with the Educational Psychology Service.

Picture Exchange Communication System (PECS)

This approach was designed for use with young children who have difficulty using language for a range of basic social purposes. It is highly adaptable to the requirements of the individual. Children with ASD not only have difficulty learning speech and language, but also learning how, with whom, why and when to communicate. PECS aims to teach functional (i.e. useful) communication skills and spontaneous communication. The basic principle involves the use of printed symbols (on cards) which the child learns to select and hand to an adult in order to communicate with them. For example, at the simplest level, the child may learn to hand over a picture of a biscuit when they want one. The system can become much more sophisticated than this as the child progresses, moving on to the use of printed words and sentences as well as pictures. The child can then have their own, portable 'communication system' of symbols that goes wherever they do and may be used instead of or to back up their spoken language. A PECS programme is most likely to be set up and monitored by a Speech and Language Therapist following their assessment of the child's communicative abilities.



For more information please contact: Your child's Speech and Language Therapist or a Specialist Speech and Language Therapist at The Meadow Centre. You can also contact <http://www.pecs.com>

Musical Interaction Therapy

This approach has been developed by Sutherland House School a National Autistic Society School. Speech and Language Therapists are familiar with this approach to developing early communication and interaction skills. It recognises that development of normal communication happens through a process in which the baby and familiar adults engage in a series of increasingly complex interactions, in which the baby takes a very active part. Adults are sensitive to the child's interests and use these to build early interactions. Musical instruments are used as a tool to encourage interest and early turn taking. This approach tends to create for the child a practical understanding of the possibility of dialogue and interaction and to develop a relationship with the adult.

Examples of activities may be:

- Tuning in to the child by joining in and copying his/her actions or sounds, perhaps using simple instruments and behaving as if they were intentional attempts to communicate.
- Singing a running commentary song about what the child is doing
- Singing personalised action songs e.g. pausing for the child to indicate a body part / toy e.g. tickling your tummy, tickling the teddy.
- Leaving dramatic pauses in a song before an important key word for the child to fill in some way i.e. a look, sound, sign, gesture, partial word, whole word.



For more information please contact: your child's Speech and Language Therapist.

Social Stories

This technique involves writing a short story that gives the person with ASD accurate information about a situation they have encountered (or are about to encounter) so as to help them understand that situation and respond appropriately. The basic format is as follows:

1. Accurately describe the situation in terms of where, who, what and why.
2. Explain the viewpoint and feelings of other people in the situation (if necessary).
3. State what the person is expected to do or say ("I will try to", "I can").
4. Develop ways of helping the person remember what to do or how to understand the situation.

These stories can be used for all manner of purposes - to explain social situations, to reinforce new skills, to explain difficult concepts, to address challenging behaviours and so on. The format and content of the story depends on the needs and abilities of the person.

For further information, you can contact: School SENCO / Educational Psychology Service / Learning Support Service/ Contact at The Meadow Centre. You might also contact http://www.thegrayentre.org/carol_gray.htm

Social Skills Training (SST)

This may involve teaching specific social rules and skills (listening, conversational turn taking, how to greet people, sharing etc.) or at a more sophisticated level it may focus on social problem solving (ways of working out what to do in a difficult social situation). Formal SST is often carried out in groups, but it can also form part of the child's everyday life if adults explain situations as they arise or prompt the child as to how to behave. The difficulty for children with ASD is that they often have trouble carrying over what they have learned in one situation to another one. It is therefore important to relate what is being taught very closely to the child's natural environment and to use repetition in the teaching. Social stories may help with this.



For more information please contact: Speech and Language Therapist / SENCO / Educational Psychology Service / Learning Support Service/ Contact at The Meadow Centre.

How Can I Use These Ideas At Home?

You don't necessarily need to embark wholeheartedly on one programme to make use of the ideas it offers. Most schools will use a combination of strategies from different programmes, and you can do the same. For example:

- From TEACCH: you can use structure and routine at home, you can make your own visual timetables to teach your child about sequences of events and warn them of changes to routine, you can think about how the environment is organised (for example is there a dedicated space for homework?).
- From Higashi: regular exercise may help your child to concentrate and reduce challenging behaviour.
- From Applied Behaviour Analysis/Lovaas: breaking down tasks into small steps and using rewards and repetition of learning experiences can help your child to acquire new skills.
- From Options: following your child's lead in play activities can help you to become accepted into their world and may then make it easier to bring them into yours.
- Social Stories can be used at home, school, and can help transfer skills from one setting to another. You may need a little help at first, but once you have got the idea you can use them as you choose.
- Social Skills Training can involve you giving your child feedback about their behaviour in a situation and helping them think about what they could have done differently. Or you can be more direct and prompt your child about how to behave in a situation - keep repeating this and it will help them to learn.

Having said all of that, your child needs time to relax and do his or her own thing (as do you). It is important to spend time just enjoying your child and not to feel as though you should constantly be teaching him/her. Don't overload your child or yourself by trying too many things at once (one thing at a time is best), and don't give up on a strategy if it doesn't work immediately. Seek advice from the professionals involved in your child's care or from other parents and voluntary organisations.

Making Informed Choices

The simple fact is that an enormous variety and number of approaches are used to help children with ASD. Those described above are some of the most well-known and widely used, however the more you read the more different ideas you will come across, especially if you use the Internet. More unusual or specialist approaches may well not be available via the NHS or LEA, so you may find yourself considering pursuing help privately. The choice can be confusing, and parents often feel that they should try everything they can to help their child. However, it is important to be aware of a few factors:

- Not every approach has been systematically and scientifically demonstrated to be effective.
- Most approaches are not effective for every child with ASD, and it is not always possible to know beforehand whether your child will benefit.
- Be wary about anything that seems to promise a "miracle cure" - this is extremely unlikely.

QUESTIONS TO ASK

If you are thinking of trying something new, and especially if you are paying for it, there are some questions that you might find it useful to ask:

- What training, qualifications or experience does the person offering the intervention have?
- Is there a way to tell whether this approach is likely to help your child? What assessment will be done before starting the intervention?
- How will progress be measured?
- What are the overall costs likely to be? Think about time, effort and any restrictions or alterations to family lifestyle, as well as finances.
- What are the likely long-term effects? How does this weigh up against the costs (financial and otherwise)?
- Are there likely to be any negative effects of the approach for your child or the family as a whole?

Voluntary organisations and support groups are useful sources of information - somebody else may have tried the approach you are thinking of. However, your experience of it may be very different.

Section 5: Growing up - the teenage years into adulthood

Developmental Issues: personal, social and health issues

For many of your children, adolescence and adulthood will be a long way away. It is important to stress that the needs of your child are likely to change as they grow and mature. You and they are likely to develop useful skills and strategies, which can be built upon as time goes by. The purpose of this section is to explore some of the issues that can arise as children with ASD grow into teenagers and young adults, and suggest some useful coping strategies. None or some of the issues might be relevant to your son or daughter. It is important to remember that alongside 'issues' there can also be new opportunities, new understanding and new skills developing. You might decide that this section is not relevant for you to read right now, but it is here for you to consider for the future.

The move from primary to secondary school raises challenges for all children. There are increased demands on children's organisation skills, social and independence skills. They move from working with 2-3 teachers to working with many teachers, having to find different classes and negotiate timetables. Since teachers have less contact with each student it is helpful if a named key person can communicate the strengths and needs of your child with all the staff teaching him/her. It is important that the information that your child's primary school has gained about him/her and the valuable information you have are taken into account. This information exchange can support staff in understanding your child's needs and adapting, as far as is possible the way they work with him/her. Look back at section 3 to Effective ways to help prepare your child for a change of

school, for some ideas about how to support a transition to a new school.

In the early teenage years, there is increased pressure to conform within the peer group and young people with ASD may find themselves at risk of being teased, misunderstood or left out of peer interaction. Many wish to make friends and fit in and if they are unable to do so may become withdrawn, and at risk of depression. Parents need to be aware of the signs of anxiety and depression. If the child becomes unusually withdrawn, has sudden outbursts of tears or temper, loses his or her appetite, has difficulty in sleeping and loses interest in the things that he or she used to enjoy, this could be a sign of depression. A General Practitioner would be able to advise further in this instance, further referral to Child and Adolescent Mental Health Services might be appropriate in some cases (see section 4 for details).

By late adolescence, other's tolerance for individual eccentricity and difference begins to increase. There may be opportunities to join clubs and social groups associated with special interests. Friendships might be made with others with similar interests. Some young people with ASD will remain largely solitary in their interests and habits and be unwilling to venture out of their familiar surroundings. Other youngsters may want to enjoy a measure of independence. They are likely to need clear guidance and boundaries as they may well be quite vulnerable and susceptible to peer pressure.

It is important to remember that the teenage years can be a difficult time for all. Teenagers have to learn to cope with hormonal changes and the physical changes and emotional reactions related to puberty. They can become tearful, argumentative and or aggressive. For a child with an Autism Spectrum Disorder, these changes can be doubly confusing. They too have the hormone surges and changing bodies but they may also have the added dislike of change and lack of understanding or awareness. Unlike typically developing children, who often seem to want to grow up too quickly, a child with ASD may resist or ignore these changes. For some girls this may be shown in resisting the need to wear a bra or showing distress about having menstrual periods. As with all change, these situations will need to be handled sensitively. Hygiene issues can be a difficulty for both boys and girls. Visual timetables and a social story approach can continue to be useful tools in encouraging adolescents with ASD to wash, change their clothes and generally take care of personal hygiene.

Adolescent sexuality can also be an area of difficulty. Young people with ASD may not be aware of the social rules surrounding overt sexual behaviour as their typically-developing peers. Boys in particular, may need clear guidance and boundaries with regard to self-stimulation and the need to keep such activities private. Adolescent boys and girls with ASD who have a tendency to be over-friendly with strangers or who have a poor understanding of personal space may also be vulnerable to inappropriate sexual advances. Youngsters may need specific support and teaching to enable them to develop a knowledge of these rules to guide their behaviour. Once again a visual or social story approach may be helpful.

SOME USEFUL APPROACHES

Helping your daughter/son to develop an understanding of their own strengths and difficulties, this might include discussion and teaching about their specific diagnosis.

All young people and indeed adults can benefit from an awareness of their own strengths and difficulties. For some this requires explicit feedback and teaching. An awareness of difficulties is best taught in conjunction with supportive strategies. For youngsters with ASD who have an awareness that they are different from others, it can be helpful to be given an explanation by sharing information about diagnosis, what this means in terms of both strengths and difficulties and ways of managing the difficulties. Luke Jackson, a teenager who has a diagnosis of Asperger Syndrome explains in his excellent book *'Freaks, Geeks and Asperger Syndrome : A Users Guide to Adolescence'* how important it was for him to know about his diagnosis.

Your knowledge of your own child will determine whether, when and how you decide to share information about their diagnosis. You might find it helpful to discuss the pros and cons of this and ask advice from any of the following:

- Other parents with a young person with an ASD – Contact Solihull SNAP or SPACE (See Section 6 for details)
- Autism West Midlands or The National Autistic Society (See Section 6 for details)
- Teachers or other professionals working with your son/daughter.

Section 7 includes a list of books for children and young people, which can be used to support discussions about strengths and difficulties related to ASDs.

Building Peer Support

The following might be useful ways of building friendships or increasing contact with others and decreasing isolation. An essential ingredient of peer support approaches involves building awareness and understanding amongst peers, of the strengths and difficulties experienced by a person with an ASD. The young person should always be consulted about sharing information with others about their diagnosis.

Peer support can be encouraged using:

- Circles of Friends (see section 4)
- Buddying, when another young person is encouraged to support your son/daughter for specific activities, this may involve the 'buddy' or 'buddy pair', receiving some training.
- Special interest clubs e.g. Chess Club, Computer Club, Comic Club
- E-mail pals.
- Pen pals

Clear and direct teaching to help social understanding and relationships

To support your son/daughter with a situation they find difficult it will be important to consider what the 'hidden' rules are operating in the situation. The following might then be used to develop a new understanding of the situation, teach new skills and give guidance about what to do:

- Comic strip conversations information about these can be found at www.thegraycentre.org/carol_gray.htm
- Social Stories (See Section 4)
- Role play
- Use of video feedback



For more information about any of these approaches speak to your contact at The Meadow Centre or The Educational Psychology Service (contact numbers can be found in section 6).

Clear teaching about changes related to puberty

Direct teaching about both the physical and emotional changes, which occur around puberty, are likely to be of benefit. In addition to school Personal and Social Development education sessions, teaching will need to be responsive to your son/daughter's particular needs. Visual approaches are likely to aid understanding and can be used as prompts e.g. through new care and hygiene routines. Colour coded Comic Strip Conversations can help to discuss emotions. Social Stories can also help to rehearse social 'rules'.

Valuing people: A new strategy for learning disability in the 21st Century

The Government have written a white paper called 'Valuing People', which is about their ideas on how to get services right for all people with learning disabilities.

'Valuing People' is based on four main beliefs about people with learning disability:

1. They are citizens too
2. They can move on and be independent
3. They can speak up for themselves
4. They can have just as good a life.

Learning Disability Partnership Boards have been set up since October 2001 in all Local Authorities. These boards have representatives from people with learning disabilities and their families, education, health, social care (formerly social services), housing, community development, and the employment service. Partnership boards are responsible for reviewing (by January 2002) and implementing the local learning disability plan.

Some of the key elements of plans are;

- Overseeing the introduction of person centred planning and approaches (see description below) for people with learning disabilities, which means that planning of support must begin with the individual, and not the services.
- Modernising day services, to allow for more flexible and person-centred approaches to provision.
- Allow greater access to advocacy.
- Develop supported living, especially for people currently living with older carers.

- Develop local services for people with behaviour that challenges.
- Helping to complete the move of people from long stay hospitals into the local community (by 2004).
- Reducing health inequalities

The White Paper and people with Asperger syndrome or 'higher level autism spectrum disorders.

There has been some concern about the ambiguity of the new definition of learning disability employed in the White Paper. Where the definition refers to autism spectrum disorders, it has been expressed in a way that leaves it wide open to interpretation by each local authority, and could mean that people with higher level autism spectrum disorders are excluded from learning disability services in future.

We have been assured that it was not the intention of the Government to exclude people with autism and Asperger syndrome for whom learning disability services are appropriate. When asked about the exclusion of people with higher level autism spectrum disorders or Asperger syndrome, the Secretary of State for Health, Alan Milburn said:

"It is important to emphasise that "Valuing People" does not preclude other people with autism from using learning disability services where they find them helpful...."

....Health and local authorities should ensure that the particular health and social care needs of each person with autism are met with genuine choices for both clients and families, through the most appropriate community based services..."

The vision for Partnership Boards is one in which power is shared and people with learning disabilities (and autism) and their families are involved as equals.

For a copy of the white paper

- Check out your local library.
- Copies of the Valuing People: a new Strategy for Learning Disability in the 21st Century (Cm Paper 5086) are available from the Stationery Office (price £15.90) - Tel: 0845 0 023474 fax orders: 0870 600 5533 e-mail: book.orders@theso.co.uk www.ukstate.com
- The Department of Health website at www.doh.gov.uk/disabilities/strategy.htm
- 'Nothing About Us Without Us', is a more accessible version of the white paper and has involved service users. It is presented in a visual, readable form at <http://www.doh.gov.uk/learningdisabilities/access/nothingabout/index.htm>

Reference: Autism Action - National Autistic Society campaigns bulletin
National Autistic Society, 393 City Road, London EC1v 1NG

Adult services

The services currently available for people over the age of 18 with learning difficulties are outlined below. These services are not ASD specific, though an Autism Services Development Officer has recently been appointed and will have the role of developing Adult Services for those with ASD, this will include staff training.



The Autism Services Development Officer can be contacted at:
Oliver House
Tel: 0121 779 5729
or at autism.westmidlands@nhs.uk
18 Highfield Road
Edgbaston
Birmingham
0121 450 7582

CONNEXIONS SERVICE

The Connexions Service is being set up in England to ensure the smooth transition from adolescence to adulthood, so that every young person has the best possible start in life. Its aim is to provide all teenagers with the help and support they need to participate in learning and achieve their potential.

Solihull Connexions was launched in September 2002. The Careers and Youth and Community Services have been brought together under the Connexions Banner. Under Connexions, the provision of services will be extended for young people between the ages of 19 and 25 (before 25th birthday) who have Learning Difficulties and/or Disabilities.



For more information please contact:
Connexions Birmingham & Solihull
331-333 Stratford Road
Shirley
Solihull
B90 3BL
Tel: 0121 251 1825

Please refer to Section 3 for further information.

Adults

Central Careers offers advice and guidance service to adults but, as Central Careers is a private company it may be that some of these services have a fee attached. Central Careers can be contacted at the Connexions address above.

SERVICES FOR PEOPLE WITH LEARNING DISABILITIES

These services are provided by Solihull Primary Care Trust which is part of the National Health Service. The Services for People with Learning Disabilities offer a variety of services for adults and children with learning disabilities who have additional health needs. The services main base is at:



Oliver House
Coleshill Road
Marston Green,
Birmingham, B37 7HL
Tel: 0121 779 5860
and can be accessed between 9 am
and 5 pm between Monday and Friday.

Psychiatry Service

Based at Oliver House, this service provides a service for adults and children with complex needs, including challenging behaviour and mental health needs.

Assessment and Treatment Units

Ivy Lodge

This is a recently-formed Assessment and Treatment Unit for adults with complex health needs and challenging behaviours.

Gilliver Road

This unit is for people with learning disabilities who have additional physical health needs.

Psychology Service

Adults with learning disabilities can be referred to Clinical Psychologists by a variety of people e.g. GP, social worker, teacher, family member. Clinical Psychologists can help clients to learn new independence skills (e.g. communication, social skills, self-care, daily living skills), cope with

difficult behaviour problems, and plan for the future. This can involve advice, assessment, skills teaching and support for the person, their family or carers.



For more information please contact:
Psychology Service
5/6 Downing Close
Off Station Road
Knowle
Solihull B92 0QC
Tel: 01564 771 877

Speech and Language Therapy Service

Speech and Language Therapy (sometimes known as Communication Therapy) can help people who have difficulties in communication (both understanding and expression). Speech and language therapists assess an individual's abilities and communication needs and, working together with families and carers, may suggest strategies for improving communication. Alternative and augmentative communication strategies are sometimes employed. These may include working with pictorial representations (e.g. Makaton symbols, photographs, etc.) or with different textures or fragrances. Speech and Language Therapy may also assist those recovering from stroke and those people with swallowing difficulties.



The Speech and Language Therapy Service is based at
20 Union Road
Solihull B91 3EF
Tel: 0121 711 7171

or can be accessed through:
5/6 Downing Close
Off Station Road
Knowle
Solihull B92 0QC
Tel: 01564 771 877

Residential Services

In partnership with Bromford and Carinthia Housing Association, Solihull PCT provides residential homes across the borough for adults with learning disabilities.

Respite Team

The respite team is based at Oliver House.

There are three respite services, that offer short stays for adults or children:

Lyndon House is for children with additional health needs.

Ivy Lodge is for people with complex needs including challenging behaviours.

Gilliver Road is for people with additional physical health needs.

Community Nursing

Learning Disability nurses work with adults and children who have a learning disability and a health care need, who have a Solihull G.P. The nurses work directly with families in their homes. They assess, plan, implement and evaluate programmes of care around health needs such as: behaviour, health promotion, personal relationships, continence. The nurses also work closely with other agencies i.e. social care, education, Child and Adolescent Mental Health Service (CAHMS).



For more information please contact:
Oliver House
Coleshill Road
Marston Green
Birmingham B37 7HL
Tel: 0121 779 5860



Social Care
Avis Taylor
Tel: 0121 704 7470 (E1)

SOLIHULL ACTION THROUGH ADVOCACY

Solihull Action Through Advocacy is a Registered Charity working with people with a learning disability and receives funding from The National Lottery and other Trust Funds and grant giving organisations. It is an independent organisation, managed by a Board of Trustees.

The charity is committed to providing a free and independent service to people with a learning disability residing in the Borough of Solihull to enable them to be fully involved and valued members of the local community.

Aims:

- Listen to their views and aspirations.
- Support them to take more control over their own lives with more opportunity for choice and independence.
- Offer long term friendship and support
- Represent their interests in discussion and consultation with service providers and exercise influence in service provision and policy making.
- Enable them to speak up for themselves wherever possible
- To ensure that individuals do not suffer through lack of ability to express their needs effectively.



For more information please contact:
Solihull Action Through Advocacy
332 Stratford Road
Shirley
Solihull B90 3DN
Tel: 0121 733 2434

Reference: Befriending & Support for People with a Learning Disability **Citizens Advocacy, Solihull.**

PERSON CENTRED PLANNING

What is Person Centred Planning?

Person centred planning is a fundamentally different way of seeing and working with people with disabilities. Being 'person centred' or using a 'person centred approach' means ensuring that everything we do is based upon what is important to a person from their own perspective. Person centred planning discovers and acts on what is important to a person.

Person centred planning helps us do this by discovering and acting on what matters to a person. It gives us a structure to help us continually listen and learn about what is important to a person now and in the future and to act on this in alliance with friends and family. It requires a fundamental shift of thinking from a 'power over' relationship to a 'power with' relationship.

The Five Key Features of Person Centred Planning

The person centred planning guidance describes 5 Key features that help distinguish it from other forms of planning

1. The person is at the centre:

Person centred planning is rooted in the principles of rights, independence and choice. It requires careful listening to the person and results in informed choice about how a person wants to live and what supports best suit the individual.

2. Family members and friends are full partners:

Person centred planning puts people in context of their family and communities. The contributions that friends and families can make are recognised and valued and gives a forum for creatively negotiating conflicts about what is safe, possible or desirable to improve a persons life.

3. Person centred planning reflects a person's capacities, what is important to a person

(now and for the future) and specifies the support they require to make a valued contribution to their community. Services are delivered in the context of the life a person chooses and not about slotting people into 'gaps'.

4. Person centred planning builds a shared commitment to action that recognises a person's rights.

It is an ongoing process of working together to make changes that the person and those close to them agree will improve a person's quality of life.

5. Person centred planning leads to continual listening, learning and action and helps the person get what they want out of life.

Learning from planning can not only inform individuals but can affect service delivery as a whole and inform and inspire others to achieve greater things.

Person centred planning is not...

- The same as assessment and care planning: it is not concerned with eligibility for resources or other predetermined criteria.
- Only for people who are 'easy to work with: It is applicable and useful for anyone regardless of ability, how they may challenge services or cultural background
- An end in itself: Person centred planning can be a powerful tool in enabling someone to change their lives, however there are serious risks in focussing on achieving large numbers of plans rather than people getting the lives they want.
- A replacement for other necessary forms of planning. For example services may need to plan in ways that help them ensure services are competent and reliable, however it is important that other forms of planning reflect and respond to person centred planning.

Why is it important?

Person centred Planning is not a means to an end in itself. If it is to be effective it must result in real change for people with disabilities. The purpose of person centred planning is to enable people to live the lives they want to in their communities.

People who have used person centred planning are finding that it can:

- Help people work out what they want in their lives and make them feel stronger and more confident
- Clarify what support people need to pursue their aspirations
- Bring people together to support people in joint problem solving and to energise and motivate people based upon better understanding of and commitment to the person.
- Help direct and shape the contributions made from service agencies, to ensure they are based upon what is important to a person from their perspective.

Person centred planning is particularly important as it is a key element in helping to deliver the governments objectives outlined in the valuing people white paper. Valuing people states: Development of a person centred approach requires real changes in organisational culture and practice. Achieving these changes should be a priority for partnership boards

In Solihull

In Solihull Primary Care Trust and Social Services 'Me and My Life' is being developed as a more person-centred approach to planning with people within Services. There is a Person-Centred Working Party which co-ordinates and monitors work in this area and reports to the Learning Disability Partnership Board. Training is underway in all Services to develop more Person-Centred Planning and approaches.

References

Luke Jackson, 2002, '*Freaks, Geeks and Asperger Syndrome: A Users Guide to Adolescence*: Jessica Kingsley pubs.

Department of Health (2001) '*Valuing People: a new Strategy for Learning Disability in the 21st Century* (Cm Paper 5086) Stationery Office

Department of Health (2001) '*Nothing About Us Without Us*', available at <http://www.doh.gov.uk/learningdisabilities/access/nothingabout/index.htm>

Autism Action - National Autistic Society campaigns bulletin National Autistic Society

Section 6: Who can help?

As a parent or carer of a child diagnosed with an Autism Spectrum Disorder, there are a variety of services that you are likely to have working with you and your child. Often parents have commented on feeling 'overwhelmed' by having 'yet another professional to see'. It can be hard to keep track of all of those who are or have worked with your child. Some parents have found it helpful to record details of all those involved with their child, to make it easier to maintain contact and inform others of those involved. You may find the following helpful, it includes key professionals that are likely to be involved, spaces are left for you to fill in any other names and contact details.

Key contacts chart

PROFESSIONAL	NAME	CONTACT DETAILS
Teacher		
Support Assistant		
SENCO		
Learning Support Service:		Solihull Learning Support Service, Woodlands Centre, Lundy View, Smith's Wood Birmingham, B36 0LY Tel: 0121 770 6267 Fax: 0121 770 6115
Educational Psychologist		Solihull Educational Psychology Service Woodlands Centre Lundy View Smith's Wood Birmingham, B36 0LY Tel: 0121 770 6030 Fax: 0121 770 7608 e-mail: educationalpsychology@solihull.gov.uk
Solihull Parent Partnership SNAP		St Andrew's Church Centre Pike Drive Chelmsley Wood B37 7US Helpline: 0121 770 5027 Office: 0121 770 5462

PROFESSIONAL	NAME	CONTACT DETAILS
Health Visitor		North Solihull Craig Croft Clinic Tel: 0121 770 3228 South Solihull Shirley Clinic Tel: 0121 744 2516
Speech & Language Therapist		20 Union Road Solihull Tel: 0121 711 7171 ext 2297
Community Paediatrician		20 Union Road Solihull Tel: 0121 711 7171
Contact from Meadow Centre		The Meadow Centre 34/36 Faulkner Road Hobs Meadow Solihull B92 8SY Tel: 0121 722 8010
Social Worker		
Other Professionals:		
Other professionals :		

An ABC of Professionals, Support Services and the support they offer

CHILD PSYCHOTHERAPIST

Child psychotherapists have intensive training to help them understand the world as seen by the child. As well as using language, child psychotherapists are sensitive to the non verbal clues and messages that are hidden in action and play in order to make sense of what a child is communicating.

A child psychotherapist may be involved in multidisciplinary assessments or in offering an individual assessment, and possibly therapy, alongside support to parents.

CLINICAL PSYCHOLOGIST

A psychologist who usually works in the context of the health service. Trained to understand and work with developmental, emotional and behavioural issues. May be involved in assessment. May also offer support or specific advice/therapy to children and families.

COMMUNITY PAEDIATRICIAN

A medical doctor who specialises in the care of children up to the age of 19. Has specialist training in assessment and care of children with special needs. Will be involved in the statutory assessment process. May see children in clinics or schools.

EARLY YEARS TEACHER

See Learning Support Service

EDUCATIONAL PSYCHOLOGIST

A psychologist who is employed by the Local Education Authority to work with children and young people from age 2-19 years. EPs work with parents, children, staff in education settings and other professionals. An EP can provide assessment and advice regarding a range of difficulties including learning, and emotional, social and behavioural difficulties. They also deliver training and work with schools to develop

areas of practice. Contact with the Educational Psychologist is co-ordinated by the SENCo. If statutory assessment is required, an EP will always be involved.

HEALTH VISITOR

A nurse who works in the community with families and young children. See Section 4 for more information.

LEARNING SUPPORT SERVICE

Teams of teachers and in some cases Special Support Assistants who support schools in their work with children with a range of Special Educational Needs.

Early Years Teachers work for the Learning Support Service. They work both with parents at home and with a range of children and staff in school nurseries, day nurseries and playgroups. The purpose of their support is to teach and assess your child over a period of time.

School age children who have a diagnosis of an Autism Spectrum Disorder might have some input from one of the specialist teachers from the **Learning and Communication Difficulties Team**. This teacher may become involved in assessing your child's progress, advising on useful strategies and approaches, offering training to staff and liaising with other professionals.

If a child has a range of difficulties advice may be sought from other teams e.g.

- Emotional, Social and Behavioural Difficulties
- Multi-sensory Impairment
- Visual Impairment
- Hearing Impairment

NURSERY NURSE

A nursery nurse is trained in the assessment of play and social skills and child development. They often work as a member of a team.

OCCUPATIONAL THERAPIST

Occupational Therapists aim to assist children to participate in daily activities and tasks as independently as possible. An occupational therapy assessment will include an evaluation of your child's functioning in self-care, play skills and learning skills.

People with an ASD can sometimes have difficulty using incoming sensory information. This can be seen in the way they respond to certain sounds smells, touch, the way they hold their bodies and move through space. Occupational Therapists are skilled in identifying how these kinds of difficulties interfere with daily life activities.

Occupational Therapists might recommend ways of adapting activities or the environment to help reduce the impact of these unusual sensory responses to sensory information.

PARENT PARTNERSHIP SERVICE

Each Local Education Authority must provide a Parent Partnership Service to offer parents and carers accurate, neutral information on their rights, roles and responsibilities within the Special Educational Needs process, and on the range of options that are available for their children's education. Parent Partnership must also provide access to an Independent Parental Supporter for all parents who want one.

In Solihull the Parent Partnership Service is run by Solihull SNAP, an independent, voluntary organisation which supports parents and carers of children with special needs. Solihull SNAP has trained staff and volunteers who can give information and support to parents and carers.

PHYSIOTHERAPIST

Physiotherapists assess children's gross motor skills and how they move around. They can advise on any aids that may be needed and can refer for adaptations to footwear if this is necessary. They can devise a programme of exercises or play to help with co-ordination and balance difficulties.

PSYCHIATRIST

A medical doctor who specialises in assessment and treatment of complex emotional, behavioural and psychiatric difficulties.

SENCO (Special Educational Needs Co-ordinator)

A Special Educational Needs Co-ordinator (SENCo), is a teacher in the school or educational setting who is responsible for the day to day running of the SEN policy. SENCOs meet and talk with parents, staff and other professionals or support agencies in order to identify special needs, plan appropriate support and monitor and evaluate progress. They might also work directly with your child, though the daily work with your child remains the responsibility of their class teacher or key worker.

SPECIAL EDUCATIONAL NEEDS OFFICER

A Local Education Authority Education Officer responsible for making placement decisions for children with Special Educational Needs.

SOCIAL WORKER

Social workers work for the Local Authority. They assess the social and care needs of children with learning disabilities and help families obtain the services they need. Social workers also carry out carers assessments for parents or carers of a child with a disability.

SPEECH AND LANGUAGE THERAPIST

Trained in assessment and treatment of a range of speech, language and communication difficulties. Some also have specialist training in feeding. See Section 4 for more information.

STATEMENTING OFFICER/NAMED OFFICER

The person at the LEA who deals with your child's case when the LEA has made a decision to go ahead with a statutory assessment of their special educational needs.

Voluntary organisations - Local links

SNAP Solihull Special Needs Active Partnership	St Andrew's Church Centre Pike Drive Chelmsley Wood B37 7US	Helpline: 0121 770 5027 Office: 0121 770 5462
SPACE Support for Parents and Autistic Children Everywhere A local support group.	Julie Jones	Tel: 0121 603 9014
Autism West Midlands formerly WMAS West Midlands Autistic Society	Head Office 18 Highfield Road Edgbaston Birmingham B15 3DU	Tel: 0121 450 7580
Solihull Kids	Information Website	http://solihull.dsk.co.uk/solihullkids/
AFASIC Association For All Speech Impaired Children	West Midlands contact: (for membership details) Use National Helpline for other enquiries.	Linda Pegler (0121 241 2788) Tel: 0845 355 55 77

Voluntary organisations - National links

NAS National Autistic Society	393 City Road London EC1V 1NG	Tel: 0207 833 2299 Fax: 0207 833 9666 e-mail: nas@nas.org.uk www.nas.org.uk
National Autistic Society Advocacy for Education Services		Education Advice Line: 0800 358 8667 Tribunal Support Scheme: 0800 358 8668
AFASIC Association For All Speech Impaired Children	2nd Floor 50-52 Great Sutton Street London EC1V 0DJ	Tel: (administration) 020 7490 9410 Fax: 020 7251 2834 e-mail: info@afasic.org.uk www.afasic.org.uk
AIA Allergy Induced Autism	8 Hollie Lucas Road, Kings Heath, Birmingham B13 0QL	e-mail: aia@kessick.demon.co.uk
Autism Research Unit For research information on diets and Urine Test	Paul Shattock Autism Research Unit School of Health & Science University of Sunderland Sunderland SR2 7EE	Tel: 0191 510 8922 Fax: 0191 567 0420 e-mail: aru@sunderland.ac.uk http://osiris.sunderland.ac.uk/autism/
Network 81 Information on statementing and runs courses for parents	1-7 Woodfield Terrace Chapel Hill Stanstead Essex CM24 8AJ	Tel: 01279 647415
ACE Advisory Centre for Autism	1b Aberdeen Studios 22 Highbury Grove London N5 2EA	Tel: 0207 354 8321 From 2-5pm Mon-Fri

Voluntary organisations - National links cont...

Autism Services	The Disabilities Trust First Floor 32 Market Place Burgess Hill West Sussex RH15 9NP	Tel: 01444 239123 Fax: 01444 244978 e-mail: Info@dissabilities-trust.org.uk www.dissabilities-trust.org.uk
IPSEA Independent Panel for Special Educational Advice	22 Warren Hill Woodbridge Suffolk IP12 4DU	Tel: 01394 382814
Dyspraxia Foundation	8 West Alley Hitchin Hertfordshire SG5 1EG	e-mail: admin@dyspraxiafoundation.org.uk Tel: 01462 454986.
BILD British Institute of Learning Disabilities	Marie Davies BILD Campion House Green Street Kidderminster, DY10 1JL	Tel: 01562 723015 Fax: 01562 723029 www.bild.org.uk
Learning Disability Helpline	123 Golden Lane London EC1Y 0RT	Tel: 0808 808 1111 Free 24 hour helpline for advice and information help@mencap.org.uk

Section 7: References

Many of the books and videos mentioned are available through the National Autistic Society. The Parent Resource Room at the Meadow Centre will have a selection of books and videos available for reference. You could also ask your local library to order books for you to borrow.

Key texts have been highlighted.

Books

ASD - GENERAL

Lorna Wing	1998	<i>The autistic spectrum: a guide for parents and professionals</i>	Constable
Maureen Aarons & Tessa Gittens	1999	<i>The Handbook of Autism: a guide for parents and professionals (2nd Edition)</i>	Routledge
The National Autistic Society	2000	<i>Autism Handbook</i>	National Autistic Society
Stella Waterhouse	1999	<i>A positive approach to Autism</i>	Jessica Kingsley Publishers Ltd.
Tony Atwood	1998	<i>Asperger's Syndrome: A Guide for Parents and Professionals</i>	Jessica Kingsley Publishers Ltd.
Lise Pyles	2002	<i>Hitchhiking through Asperger Syndrome</i>	Jessica Kingsley Publishers Ltd.

TEACHING AND LEARNING

Jordan and Jones	1999	<i>Meeting the Needs of Children with Autistic Spectrum Disorders</i>	David Fulton Publishers Ltd.
Jordan and Powell	1998	<i>Understanding and Teaching Children with Autism</i>	John Wiley & Sons
Shira Richman	2000	<i>Raising a Child with Autism: A Guide to Applied Behaviour Analysis for Parents</i>	Jessica Kingsley Publishers Ltd.
Jordan and Powell	1997	<i>Autism and Learning: A Guide to Good Practice</i>	David Fulton Publishers Ltd.
Cumine, Leach, and Stevenson	1998	<i>Asperger Syndrome: A Practical Guide for Teachers</i>	David Fulton Publishers Ltd.
Leicester City Council	1998	<i>Asperger Syndrome - practical strategies for the classroom : A Teachers Guide</i>	National Autistic Society
Brenda Smith Myles & Jack Southwicke	1999	<i>Asperger Syndrome and Difficult Moments: Practical Solutions for Tantrums, Rage and Meltdowns</i>	Autism Asperger Publishing Company

Brenda Smith Myles & Diane Adreon	2001	<i>Asperger Syndrome & Adolescence: Practical Solutions for School Success</i>	Autism Asperger Publishing Available from Jessica Kingsley
-----------------------------------	------	------------------------------------------------------------------------------------	---------------------------------------------------------------

Matthew Hesmondhalgh & Christine Breakey	2001	<i>Access and Inclusion for Children with Autistic Spectrum Disorders 'Let Me In'</i>	Jessica Kingsley Publishers Ltd.
------------------------------------------	------	---------------------------------------------------------------------------------------	----------------------------------

DEVELOPMENT OF SOCIAL SKILLS AND UNDERSTANDING

Patricia Howlin, Simon Baron-Cohen & Julie Hadwin	1999	<i>Teaching Children with Autism to Mind Read</i>	Wiley
---------------------------------------------------	------	---------------------------------------------------	-------

Rebecca Moyes	2001	<i>Incorporating Social Goals in the Classroom: A Guide for Teachers and Parents of Children with High Functioning Autism and Asperger Syndrome.</i>	Jessica Kingsley Publishers Ltd.
---------------	------	------------------------------------------------------------------------------------------------------------------------------------------------------	----------------------------------

Carol Gray	2002	<i>My Social Stories Book</i>	Jessica Kingsley Publishers Ltd
------------	------	-------------------------------	---------------------------------

COMMUNICATION

Manolson	1992	<i>It Takes Two to Talk</i>	Hanen Centre www.hanen.org
----------	------	-----------------------------	-------------------------------

Weitzman	1992	<i>Learning Language and Loving It</i>	Hanen Centre
----------	------	----------------------------------------	--------------

Quill (Ed)	1995	<i>Teaching Children with Autism: Strategies to Enhance Communication and Socialisation</i>	Delmar Pubs. Inc.
------------	------	---------------------------------------------------------------------------------------------	-------------------

Carol Potter & Chris Whittaker	2001	<i>Enabling communication in children with Autism</i>	Jessica Kingsley Publishers Ltd
--------------------------------	------	-------------------------------------------------------	---------------------------------

Frost and Bondy	1994	<i>The Picture Exchange Communication System (PECS)</i>	PyramidEducational Consultants, UK, Ltd. Tel: 01273 728888
-----------------	------	---------------------------------------------------------	---------------------------------------------------------------

SUPPORT WITH FAMILY LIFE

Schopler (Ed)	1995	<i>Parent Survival Manual: A Guide to Crisis Resolution in Autism and Related Developmental Disorders</i>	New York Plenum Press
---------------	------	-----------------------------------------------------------------------------------------------------------	-----------------------

Martine Ives & Nell Munro	2002	<i>Caring for a Child with Autism: A Practical Guide for Parents</i>	Jessica Kingsley Publishers Ltd.
Sandra Harris	1994	<i>Siblings of Children with Autism: A Guide for Families</i>	Woodbine House
Maria Wheeler		<i>Toilet Training for Individuals with Autism and Related Disorders (A Comprehensive Guide for Parents and Teachers)</i>	Future Horizons
Julia Moor		<i>Playing, Laughing and Learning with Children on the Autistic Spectrum</i>	Jessica Kingsley Publishers Ltd.
Ross W. Greene	2001	<i>The Explosive Child</i>	Quill
Joan Matthews & James Williams		<i>The Self-Help Guide for Special Kids and their Parents</i>	Jessica Kingsley Publishers Ltd.
Philip Whitaker	2001	<i>Challenging Behaviour and Autism</i>	National Autistic Society
V.M. Durrand	1998	<i>Sleep Better! A Guide to Improving Sleep for Children with Special Needs</i>	Paul Brookes
Brenda Legge	2002	<i>Can't Eat, Won't Eat: Dietary Difficulties and Autistic Spectrum Disorders.</i>	Jessica Kingsley Publishers Ltd.
National Autistic Society		<i>Focus on the Family - Booklets 1-5: Booklet 1 - Diagnosis: Reactions in Families Booklet 2 - Understanding Difficult Behaviour Booklet 3 - Recording Behaviour Booklet 4 - Experiences of the Whole Family Booklet 5 - Recognising and Coping with Stress</i>	National Autistic Society

THE EARLY YEARS

Cumine, Leach, and Stevenson	2000	<i>Autism in the Early Years</i>	David Fulton Publishers Ltd.
Leicestershire County Council and Fosse Health Trust		<i>Autism - How to Help Your Young Child</i>	National Autistic Society
Beyer and Gammeltoft,		<i>Autism and Play</i>	Jessica Kingsley Publishers Ltd.

ADOLESCENCE

Luke Jackson	2002	<i>Freaks, Geeks & Asperger Syndrome : A User Guide to Adolescence</i>	Jessica Kingsley Publishers Ltd.
Matthew Hesmondhalgh & Christine Breakey	2001	<i>Access and Inclusion for Children with Autistic Spectrum Disorders 'Let Me In'</i>	Jessica Kingsley Publishers Ltd.

BOOKS FOR CHILDREN AND YOUNG PEOPLE

Kathy Hoopman	2001	<i>Blue Bottle Mystery : An Asperger Adventure</i>	Jessica Kingsley Publishers Ltd.
National Autistic Society		<i>What is Asperger Syndrome and How Will it Affect Me? A Guide for Young People</i>	National Autistic Society
Peter Vermeulen		<i>I am Special - Introducing Children and Young People to their Autistic Spectrum Disorder</i>	Jessica Kingsley Publishers Ltd.
Claire Sainsbury	2000	<i>Martian in the Playground: Understanding the school child with Asperger's Syndrome</i>	Lucky Duck Publishing Ltd.
Julie Davies	1994	<i>Able autistic Children-children with Asperger's Syndrome: A booklet for brothers and sisters</i>	The Early Years Diagnostic Centre
Julie Davies	1994	<i>Children with autism: A booklet for brothers and sisters</i>	The Early Years Diagnostic Centre
Louise Gorrod	1997	<i>My Brother is Different</i>	National Autistic Society
Gunilla Gerland	2000	<i>Finding Out About Asperger Syndrome, High Functioning Autism and PDD</i>	Jessica Kingsley Publishers Ltd.

ACCOUNTS FROM ADULTS WITH A DIAGNOSIS OF AN ASD

Donna Williams	1996	<i>Autism: An Inside-Out Approach</i>	Jessica Kingsley Publishers Ltd.
Donna Williams	1998	<i>Autism and Sensing: The Unlost Instinct</i>	Jessica Kingsley Publishers Ltd.
Schneider	1999	<i>Discovering My Autism</i>	

Wendy Lawson 2001 *Understanding and Working with the Spectrum of Autism* Jessica Kingsley Publishers Ltd.

SPECIAL EDUCATIONAL NEEDS/ LEARNING DISABILITY

Department for Education and Skills (DfES) 2001 *Special Educational Needs (SEN) A guide for parents and carers* DfES Publication Centre Tel: 0845 602 2260

FREE PUBLICATION Department of Health (DoH) 2001 *Valuing People: a new strategy for Learning Disability in the 21st Century* The Stationery Office

Videos

Understanding Asperger syndrome (Royal Children's Hospital)

The purpose of the video is to provide help for parents of newly diagnosed or potentially diagnosable children; for their teachers as they struggle to understand them in the classroom; and for child health professionals who need to be able to recognise and treat the disorder.

Produced by The Royal Children's Hospital, Victoria. Running time 30 mins (Code NAS389) [£30.55]

ASK ME about Asperger's Syndrome

Professionals and parents describe the impairments that typically affect students with Asperger Syndrome and offer practical suggestions and techniques for working with these children.

ASK ME is an acronym for Accepting, Structured, Kind & Supportive, Motivating, and Enriching - the key elements for providing an appropriate educational environment for students diagnosed with Asperger Syndrome.

Produced by Jessica Kingsley Publishers, 2000, running time 25 mins, (Code NAS418) ISBN 1 85302 987 4 [£29.95]

A is for autism

This award winning animation is a short glimpse into the condition of autism, all contributed by people with autism. The narration is by people with autism who are able to recount their thoughts and feelings, offering an insight into the problems and pleasures of the vast majority, who are not able to communicate or express themselves in this way.

Produced by Channel 4, 1992. Running time 11 mins. (Code NAS 240) [Price £5.99]

a to a

'a to a' shows families talking about their experience of diagnosis and the therapies that they have found to benefit their children. The video is both positive and informative covering the following therapies and intervention programmes: Auditory Integration Training, The Boston Higashi School, Lovaas - Behavioural Intervention, Facilitated Communication, SPELL, TEACCH, Son-Rise at the Opticon Institute. Each therapy is explained and demonstrated, followed by contact names and address. Produced by Paradogs 1998. Running time 60 mins (Code NAS 283) [Price £15.99]

The ages of autism

This 30-minute video focuses on the wide variety of abilities and needs of people with Autism Spectrum Disorders and highlights the need for different services and support to enable people to reach their full potential. There are interviews with a parent, people with Autism Spectrum Disorders and professionals in the field of autism. Diagnosis, early intervention, schooling and adult life are discussed and explained. This video will be useful for parents and family members in explaining the issues concerning diagnosis and the steps to follow after diagnosis. This is also useful for health professionals, providing a broad overview of this complex area.

Produced by Mark-It Television Associates, 1999. Running time 30 mins. (%) (Code NAS 072) [Price £15.99]

Autism: behind an invisible wall

This video offers parents, professionals and students a jargon-free description of autism. The video highlights the problems experienced by people with autism and gives examples of typical behaviour.

Produced by The National Autistic Society, revised 1994. Running time 24 mins 26 secs (%) (Code 211) [Price £12.99]

Children Can Learn with Their Shoes Off: Supporting Young People with Asperger's Syndrome. By Barbara Maines

This resource features excellent, flexible and imaginative ways in which adults working in schools can improve the learning and social experience for these students. It includes 12 sections as follows:

- Section 1 Who and what are we studying ?
- Section 2 Awareness and flexibility
- Section 3 Visual Clues-structured (PECS)
- Section 4 Non-verbal communication
- Section 5 Social Stories
- Section 6 Feelings and Emotions
- Section 7 Drama and Social Skills
- Section 8 Follow up work
- Section 9 Friendship and Support
- Section 10 Relaxation and Scripted Fantasy
- Section 11 Adolescence
- Section 12 Special Skills- Savantism.

Produced by Lucky Duck ISBN 1 873 942 89 3 (£40.00 + £7.00 VAT) www.luckyduck.co.uk

Internet Sites

Internet access is available for parents in the parents' room at The Meadow Centre and at the SNAP base. It is advisable to book internet use in advance at both sites, in order to avoid disappointment.

The National Autistic Society website is the key site to visit. It has information about the NAS, but also links to many other useful and interesting sites. It can be found at: www.nas.org.uk

Websites mentioned in this booklet are listed below, by section.

SECTION 2: LIVING TOGETHER AT HOME

www.childcarelink.gov.uk
www.nas.org.uk

SECTION 3: MY CHILD'S EDUCATION

www.childcarelink.gov.uk

SECTION 4: DIFFERENT WAYS OF HELPING MY CHILD TO DEVELOP AND LEARN.

www.teacch.com or <http://www.unc.edu/depts/teacch/>
www.ulst.ac.uk/pap/bostonhig.html or <http://www.musashino-higashi.org/english.htm>
www.peach.org.uk or <http://www.Lovaas.com>
www.Son-Rise.org
<http://www.pecs.com>
http://www.thegrayentre.org/carol_gray.htm

The following, though not mentioned in this section have information about resources in ASDs

<http://autismconnect.org>
<http://www.asperger.org/>
<http://www.autism-awareness.org.uk>
<http://www.autism-resources.com>
<http://www.autismuk.com>
<http://www.autism-uk.ed.ac.uk/>
<http://www.autistic.net/>
<http://www.lookingupautism.org>
<http://www.mental-health-matters.com/autism.html>
<http://www.mugsy.org>
<http://www.udel.edu/bkirby/asperger/>

SECTION 5: GROWING UP-TEENAGE YEARS INTO ADULTHOOD.

www.ukstate.com
www.bild.org.uk
http://www.thegrayentre.org/carol_gray.htm
The Department of Health website at www.doh.gov.uk/disabilities/strategy.htm

SECTION 6: WHO CAN HELP ?

www.nas.org.uk
www.afasic.org.uk
www.dissabilities-trust.org.uk

Section 8: Frequently asked questions

Diagnosis

What happens if I disagree with my child's diagnosis?

A diagnosis will always be arrived at in consultation with parents. The assessment process identifies your child's strengths as well as weaknesses and this is often seen as one of the most useful aspects of assessment and diagnosis, however, if you still disagree with the diagnosis then you can ultimately decide who you share this information with. If you disagree with the diagnosis then a second opinion can be sought.

Educational Provision

Will a diagnosis of ASD automatically result in my child being issued with a statement of Special Educational Need?

No, there are youngsters with a diagnosis of ASD who need no additional support, or who are catered for at School Action or School Action Plus. Statements are issued for a very small minority of children who have significant needs that can not be catered for without additional resources being provided by the LEA. (See Section 3 for further information)

Who can I ask to assess my child's educational needs?

Assessments of your child's progress should be regularly made by your child's school or nursery. If there are continuing concerns about the academic, behavioural, emotional or social progress which your child is making, then it may be appropriate to ask a member of the Learning Support Service or the Educational Psychology Service to become involved in the joint assessment process. Your child's school will consult with you and seek your views and permission to make any referral for assessment.

When do I get to tell people about my views of my child and his/her needs?

You have a huge amount of knowledge and expertise about your own child, it will therefore be essential that your views are listened to as part of any assessment of your child's needs. Your views will therefore be asked for whenever any concerns are expressed about your child's progress at school. It is also important that you express and discuss your views with school at any stage. This will involve sharing successes as well as sharing concerns.

If your child is at School Action, School Action Plus or has a Statement of Special Educational Needs, regular reviews will be held by the school and your views, your child's views and the views of other professionals involved will be sought. If you would like support to help you to gather and express your views you can take a family member or friend along to these reviews. SNAP can also be contacted to support you in expressing your views.

What type of support is available for my child in the local mainstream school?

A youngster with a diagnosis of ASD may be catered for in a variety of ways by their local mainstream school. Section 3 outlines the graduated approach to children's special educational needs and the type of support that is likely to be available. Section 4 outlines some of the main approaches and specific strategies often used to support youngsters with an ASD. If you are unsure of the approaches being used by staff at your child's school then arrange to meet and discuss this with your child's class teacher or the SENCo.

Will a diagnosis of ASD automatically mean that my child will go to a special school ?

No, the school placement of a child with an ASD depends on an assessment of their educational needs. Many children with a diagnosis of an ASD can be well catered for within their local mainstream schools, with the appropriate level of support. So, for example, some youngsters need no additional support, others are catered for at School Action or School Action Plus. Additional support can be provided as the result of a statutory assessment of your child's educational needs.

If I decide that I would like my child to attend a specialist school for people with ASD, will the LEA pay for this ?

The LEA have to make placement decisions based on all of the advice which is gathered in the statutory assessment of your child's Special Educational Needs. Parental advice forms a central part of the assessment process. In most cases children's needs can be met in local Solihull provisions. In rare cases a decision will be made that a child's special educational needs can not be catered for in a local authority school. In these cases the authority will explore with you the options which are available.

What happens if I disagree with the LEA's decision about providing extra support for my child ?

If you disagree with your LEA's decision about provision for your child, then you should first talk to a representative from your LEA or your child's school. You have the right to ask the LEA for informal resolution of the disagreement and a right to appeal to the Special Educational Needs Tribunal. SNAP parent partnership services might also be a useful point of contact, they can discuss all of these options with you.

What do I do if I am unhappy with my child's educational provision?

If your child is at School Action, School Action Plus, of the Code of Practice, or has a statement then you will have regular opportunities to express your concerns at review meetings.

The school SENCo or Headteacher should be approached if your concerns can not be answered.

If your concerns still persist it may be appropriate to contact SNAP, The Educational Psychology Service or an SEN officer.

Who provides training for school staff?

Training and advice for school staff is provided by a range of professionals, including members of the Learning Support Service, Educational Psychology Service and health professionals such as Speech and Language Therapists. Currently the LEA provides 'case study' training to educational settings when a child with significant Social Communication Difficulties, including Autism, attends the Nursery or Reception Class. The training gives broad information on Social Communication Difficulties including Autism and then focuses on the current specific needs of the child.

How can I find out about residential schools for my child if I have to?

SNAP, parent partnership services are a good source of information about school provisions. The National Autistic Society can also provide information about Autism Specific provisions. They publish an information booklet titled Schools Units and classes, (ISBN 1899280).

Will my child receive speech and language therapy ?

Speech and Language Therapists work in a variety of ways to support and help children with ASDs. Sometimes one to one therapy is appropriate, but often liaison and advice for parents and others involved with the child is the best way forward.

As an Autism Spectrum Disorder is a communication disorder it is possible that a speech and language therapist was the first person to recognise the signs and ask permission to refer your child for possible diagnosis.

If your child was diagnosed by a multidisciplinary team, it is likely that a speech and language therapist was involved. She will have observed him or her, carried out some formal assessment of language understanding and use and probably talked to you and possibly others about how your child communicates in different situations.

For younger children, a speech and language therapist can give advice about the importance of eye contact, sharing and joint attention as early communication develops, and about using a visual system such as PECS (Picture Exchange Communication System) if talking is slow to develop. Children with an Autism Spectrum Disorder rarely need help with speech sounds, it is usually their motivation to use speech to communicate and their lack of understanding of communication which holds back spoken language.

Some older children, particularly those with Asperger's Syndrome are likely to have good speech and language skills at least for the purposes of formal assessment. It may be that their language difficulties are 'pragmatic', that is to say, for example, they may not understand the 'give and take' of friendships or how to differentiate the way they speak to older people as opposed to their peers. A speech and language therapist may be able to give advice about these issues but one to one therapy in a community clinic is less likely to be helpful.

Will my child receive social skills training ?

As discussed in Section 4 this may involve teaching specific social rules and skills or at a more sophisticated level it may focus on social problem solving (ways of working out what to do in a difficult social situation). Many mainstream schools use 'Circle Time' as a way of establishing social skills and expectations e.g. listening, waiting for your conversational turn. Formal SST is often carried out in smaller groups, but it can also form part of the child's everyday life if adults explain situations as they arise or prompt the child as to how to behave. Social Skills groups are carried out in some schools by members of the Learning Support Service, or a member of the school staff. Speech and

Language Therapists might be involved in advising staff about setting up a group and may occasionally run groups.

The difficulty for children with ASD is that they often have trouble carrying over what they have learned in one situation to another one. It is therefore important to relate what is being taught very closely to the child's natural environment and to use repetition in the teaching. Social stories may help with this. You can talk to your school SENCo, Class Teacher, Speech and Language Therapist, Learning Support Service Teacher or Educational Psychologist if you have any queries about Social Skills Training and its appropriateness for your child.

General

Will professionals who are assessing or helping my child have specific training in ASD?

Solihull Multi-agency ASD group are currently involved in developing a training strategy across Services in Solihull.

Those involved in diagnostic assessment of your child have appropriate training and experience in ASDs. In most other Services there will be a key member of staff whose responsibility it is to inform and develop good practice within their Service.

Are there any advocacy services for people with ASD ?

The importance of listening to the child's voice when planning services and provision has been emphasised in recent government thinking. For young children parents often act as advocates given their own knowledge of their child's likes and dislikes. All schools have to help children to express their own opinions and where possible children are encouraged to give their opinions for review meetings and attend review meetings. Children need support and practice in making choices and expressing their own opinions.

Solihull Action Through Advocacy is a Registered Charity committed to providing a free and independent service to people with a learning disability residing in the Borough of Solihull to enable them to be fully involved and valued members of the local community. See section 5 more information about this service.

The British Institute of Learning Disability have a useful fact sheet about adult Advocacy and Person Centred Planning. (www.bild.org.uk).

Do people working in health, social and education services communicate with each other?

The Meadows Centre has recently been created as a multi-professional team. Representatives from Health, Education and Social Care all work within the Meadows Centre. Systems for better communication between these Services are being developed. There will be a key worker for each family whose role it will be to co-ordinate information from all of those involved. Following a diagnosis of an ASD you as parents will be asked for consent to share assessment information to other agencies e.g. schools. It is generally useful to share this information, as it supports others in making appropriate responses.