Autistic Spectrum Disorders

A Guide for Practitioners Working in Pre-School / Primary / Special school settings in Wales

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What Are Autism Spectrum Disorders?

Autism spectrum disorders (ASD) are diagnosed when a child or adult has impairments in social interaction and social communication together with impaired social imagination and a narrow repetitive pattern of activities and interests.
The term 'autism spectrum disorder' is a broad term that refers to the subgroups known as Pervasive Developmental Disorders (PDD). These subgroups include Childhood Autism, Asperger syndrome, and other autism spectrum disorders, all of which are defined by the World Health Organisation's international Classification of Mental and Behavioural Disorders.
Research evidence indicates that 1 in 100 individuals have an autistic spectrum disorder (ASD) in the UK. It is believed that within Wales today there are approximately 27,000 people with an autistic spectrum disorder. Diagnosis involves a comprehensive assessment by an experienced team of clinicians that usually includes a detailed interview with the parent, specific psychological and language assessments and clinical observations.
Referral for assessment and diagnosis enables the individual to access the most suitable support and advice and evidence shows that suitable support and early intervention provides the best outcomes for individuals with ASD. It is also important to be aware that ASD is commonly found together with other medical conditions, both physical and mental.

Although population estimates show that Autistic Spectrum Disorders are relatively common, they are under diagnosed in the current population, especially in adulthood. In addition some individuals may have particular signs of ASD without necessarily having the full syndrome of ASD that would result in a diagnosis. It is therefore important to have an awareness of the signs of the disorder as many of the people the criminal justice system come into contact with may not be aware that this is why they are experiencing difficulties. This leaflet will address issues and topics that are universal to enabling the individual to make the best use of their pre-school, primary and/or special school education.

Impact of ASD in pre-School and Primary Education settings

An understanding of how the Triad of impairments and sensory issues will affect the way a person with ASD perceives their environment is important when establishing classroom routines and delivering the curriculum. It is also important to recognise that having ASD will affect people in different ways and teaching methods and strategies must be based on an individuals' needs.

Here are some general ways in which people with ASD experience the world differently (taken from the Bridge to success programme, adapted from the Early Bird Programme by Rosie Jones and Siârlot Hall from a South Wales special school).

Sensory differences

- Can be 'hypo' (under) or 'hyper' (over) sensitive.
- Sensory perceptual differences.
- Takes longer to process information.
- Can be monotropic – able to process only one sense at a time.

Issues with sounds (auditory)

- Distractions e.g buzzing lights, TV, music, other people.
- Auditory defensive.
- May not appear to hear (have tuned into another sound other than your voice).

Issues with touch

- Flinches/screams when touched, removes clothing.
- Dislike of certain textures.
- Likes to sit in tight corners/under tables.

Issues with tastes and smells

- Only eats food of certain colours/textures/tastes.
- Resists trying new foods.
- Reacts to different smells.
- PICA – mouthing any object/substance.

Issues with proprioception/proxemics

- Do not know where their body is in space or how close to be.
- Difficulty sitting in a chair or keeping still.
- Flaps hands/arms.
- Literally 'does not know own strength'.
- Difficulties with dressing/undressing.

Issues with theory of mind

- Difficulties understanding what other people are thinking and feeling.
- Theory of mind is usually in place by four years of age. Individuals know how to get around their parents and carers by using psychology. Individuals with ASD may use their behaviour instead.

Memory

- People with ASD may store and recall memories in a different way to other people. They store their memories as discrete events. They can replay each memory exactly, but do not make connections between them, so find it difficult to anticipate events. They remember things that the rest of us have forgotten, but may have missed the point of the event.

Language levels

The language level used with an individual needs to reflect their level of understanding. Language needs to be simple, clear and unambiguous.

Helpful Ideas

Use explicit choicest; the use of visual prompts e.g. symbols and pictures will help with understanding.

Structured teaching (see TEACCH in Appendix), uses the physical room layout with explicit areas for different activities; A visual timetable where symbols are used to represent tasks/ activities Symbols can also be used to communicate (see PECS in Appendix). The individual may need tasks cued by visual, verbal or physical prompts.

Sign language may be involved by the use of 'Makaton' or 'Signalong' sign systems.

The importance of family and multi-agency working

Working with families

Regular contact with the family of an individual with ASD will be of mutual benefit. Parents will always know their child best, but staff can offer different perspectives. By working together and offering opportunities for regular dialogue, formally and informally, will enable ideas and strategies to have a stronger continuity and consistency. This improves the chance for success. The views of families will help prioritise learning plans and structure. Home-school books will inform a parent/carer of the individual's day at school and vice versa. Parent/carers will need to know how and when is an appropriate time to make contact with the school and their child's teacher/support assistant.

Multi agency collaboration

Individuals with ASD often have a large network of professionals working to support them and their families.

This support can be from:

• Speech and language therapist.
• Occupational therapist.
• Physiotherapist.
• Music therapist.
• Play therapist.

And this will help to develop supportive strategies and programmes. There will be clear lines of referring concerns to these professionals and the result may be joint working on an effective programme.

Referrals to Child and Adult Mental Health Service (CAMHS)

Specialist/outreach support teams, Social services, Carers/respite, Psychologists (Educational, Clinical) and Adult services may also be a feature of support at various times during school life.

Professionals involved in the care and education of individuals with ASD have a responsibility to communicate and collaborate with each other for the benefit of the individual and always in collaboration with parents/carers.

Transitions

The change of one set of circumstances or setting to another is called a Transition. The individual with ASD may need a lengthy preparation and planning for transition. This is best done in consultation with the professionals and parents and should take into consideration the individual's needs and likely responses.

The transfer from Primary to Secondary school at the age of 11 will concern most children. Primary schools are generally smaller communities. Secondary schools are on a much larger scale, involving multiple same age groups of pupils who attend lessons given by subject specialists. Support staff, working in the Primary school, do not generally follow the individual into Secondary phase. 'Local' secondary schools are located in areas of large population and so the individual in.

Successful transition plans for the individual with ASD will include:

- Ongoing dialogue between staff involved in transition plans from Primary and Secondary, parents and the individual themselves.
- An accurate profile of the individual being shared including their strengths, preferences and friendship group.
- Receiving staff understanding the nature of ASD and the key characteristics of particular individuals.
- A buddy/mentor system by peers available.
- Planning well in advance of the move, with preparation for the individual involving several visits at different times of the day.
- Having a visual record of the new setting, including photographs of key places and people and a chance to practise navigation of the new environment.

Other transitions

Many individuals with ASD find difficulties with transitions from one activity to another.

Helpful Ideas

Visual structures such as schedules using Objects of reference, photographs or symbols may alleviate the uncertainty and reassure the individual and help them to understand what is about to happen.

Pre School

The child with ASD may begin their pre-school placement with some difficulties around self-care skills, e.g. independent eating and toilet routines, regular sleeping habits and good communication.

Other typical issues at this age are:-

Food

Preference for certain textures, colours or types/brands of food-stuffs. Resistance to trying new foods.

Helpful Ideas

Use visual prompts (photos, objects of reference) to prepare for eating.

List preferred smells and textures and extending gradually, keeping different foods/textures separate.

Minimise demands- prioritise sitting down with an sit/eat/drink rule. Extend to sitting at a table with 1 person.

Establish routine of where they sit and how the table is laid.

Introduce food in a non-threatening way e.g. in play situations.

For narrow diets, always check with the doctor or pharmacist.

Toileting

There may not be a connection between the sensations of urinating/ defecating and using a potty, only using a nappy.

Helpful Ideas

Make a routine with the same toilet/potty in the same place.

Make a personalised 'toilet' story (see Social stories later).

Give little or no reaction to "accidents".

Use meaningful rewards – computer for 5 minutes or a book

rather than 'good boy' or 'well done'

Try to keep to the same routines and keep any other stimulation low.

Sleep

Sleeping for short periods or having difficulty in settling down to sleep may be an issue.

Helpful Ideas

Establish rule that the bedroom is only for sleeping in.

Keep sensory stimulation at a low level including access to 'entertainment' in bedroom.

Relaxation exercises like deep breathing, having a bath and a story.

Establish consistent bedtime routines.

Using the right language

Difficulties with acquisition and understanding the spoken word, reading body language, facial expressions and gestures can cause difficulties with communication.

Helpful Ideas

Make language simple and explicit. Avoid ambiguity and choices e.g. Not 'Shall we go out to play now?' – say 'Play time'.

Avoid abstract phrases such as 'Line up', / 'Make a circle', show them what is needed.

Limit choices, e.g. Not 'What do you want to play with?' Say ' Jig saw or colouring' with a visual prompt. Always give the child the opportunity and time to process language.

Primary School

Children leaving their pre-school placement will be given a choice of educational settings which is dependent upon the wishes of the parent and the provision available within the local authority.

These choices will be Primary (Welsh or English medium) mainstream class; Primary mainstream unit provision or a special school. A high number of children with an ASD will be in mainstream settings.

Training and awareness for all staff is the key to successful inclusion.

Common issues in Primary schools

"Meltdowns" can be a feature of many children with ASD. Behaviours are 99.9% a form of communication (usually that something is wrong/ has been changed/ not as anticipated) By noting when "meltdowns" occur, where and with whom, a plan of action can be formulated which includes an intervention programme to help improve communication.

Toileting problems - consistent toilet use may still not be established by primary age. A consistent toileting plan needs implementing at home and school. Using meaningful rewards is particularly important.

High levels of anxiety can often be experienced by children with ASD, maybe leading to anxiety and/or challenging and uncooperative behaviour, aggression or self-injury. It is important to identify the cause, reducing the triggers if possible.

Sharing – In the classroom there may be difficulties in turn taking, not understanding another person's point of view and waiting for your 'go'. This may also spill over into unstructured break times. Clear visual reminders may help the child to know when it is their turn and a timer or a toy microphone could be used to signal 'his turn' my turn'.Many of these difficulties are due to deficits in joint attention and social reciprocity - the ability to co-ordinate attention

with another person, and an object of interest. To promote these skills it will be necessary to improve joint attention.

Choice making – there may be difficulty in choosing because the child does not have an idea of alternatives. High levels of anxiety can result from the pressure of making choices. Show choices, rather than expecting them to come up with ideas or limit choice to 'either/or' to make choosing easier.

Decision making- reluctance to make a decision may arise from not wishing to be wrong or unpopular. Encouragement and clarity of what's on offer could help. Sometimes this may also be strength as a very logical approach can help decision-making and a person with ASD will not rely on a "gut reaction".
Therefore choices are made through a more logical process.

Appropriate support structures - the use of trained, knowledgeable, informed adult support cannot be overestimated within the primary setting. It is important that whole staff training is given and that staff are sensitive to the learning style of the young person with ASD. This should include the appropriate training to implement ASD friendly strategies. These could include visual timetables, Buddy systems and being able to provide a safe haven should the need occur.

Other Education provision

Attached unit provision

Attached units can be part of mainstream primary schools. They can often offer an eclectic mix of approaches designed to suit the individual child's needs. The benefit of an attached unit is that there are great opportunities for inclusion in the mainstream setting if it is appropriate for the child. Attached units may cater for children from 3-11.

Special Schools

A placement of a pupil with ASD in a mainstream or special school will depend on parental choice as well as an assessment of the learning needs of the pupil.

Special schools cater for a wide range of children with additional learning needs (ALN). Classes are usually small and have a good pupil: staff ratio. Staff at special schools often have additional training for in communication, positive behaviour support, sensory difficulties and ASD specific teaching strategies. Staff are increasingly being used to provide support and advice to mainstream schools.

ASD alongside other learning needs

The child with ASD may also have other diagnosed conditions e.g. allergies; bowel dysfunction, dyspraxia; dyslexia; speech and language delay; epilepsy. Younger children may still be awaiting a full assessment of their needs but are recommended for a special unit/class or school.

The child with ASD in a special school may have some strengths and weaknesses that are different to their peers.

Sometimes they can have:

• more use of spoken language.

• more self help skills.

• better self organisation.

• particular strengths in areas like number, literacy or ICT.

Conversely they can sometimes be:

• more withdrawn.

• poor at responding to other people.

• very rigid in their expectations and preferences.

• far less sociable with their peers and adults.

• poor at communicating their needs and feelings.

Special schools can use strategies like social and public praise; behaviour targets, variety of learning approaches and group language programmes to good effect with many pupils. The child with ASD is unlikely to respond to these strategies because of their core differences, related to the Triad of impairments.

Building functional communication and social skills

When children start school they are often used to communicating basic needs to their parents. Most children indicate hunger/thirst/ fatigue through a range of gestures, signs, vocal, pictures, symbols or words.

In Special schools a range of communications systems will be in use e.g. P.E.C.S (Picture Exchange Communication System, see Appendix). Some will use a mix of systems for best results. The most important part is that everyone is consistent in their approach to language in order to not confuse their child.

A positive and structured day is used to encourage positive routines, which in turn eases their anxiety in the school day. Children are encouraged to participate in a range of activities, sit at tables whilst playing with toys, and tolerate close proximity of other people. Using objects of reference, symbols and visual timetable, children are able to navigate themselves around the school independently.

Alternative curriculum, including life skills

All children have access to a mainstream curriculum, which is adapted to the children needs and ability. ICT and use of the interactive whiteboard has proved to be successful in engaging pupils. A TEACCH (see Appendix) approach is also used, focussing on clarity of task, structured beginnings and ends of tasks/sessions as well use of the traditional workstation.

A sensory curriculum can be used for children who cannot access a conventional curriculum. Specific programmes/activities can be used to develop and stimulate pupils at a multisensory level. Throughout the day pupils are given opportunities to develop their independence and life skills in preparation for adulthood.

Work between special schools and other establishments/professionals helps to ensure that transition goes smoothly by organising.

- Visits from staff from new setting to familiarize themselves with pupil and discuss particular issues with staff at school e.g. communication, likes and dislikes, sensory issues and behaviour support strategies.

- Arrange series of transition/familiarization visits to the new setting.

- Setting up Person centred planning meetings with all professionals concerned.

Whatever the transition is, always find time to discuss any genuine concerns individuals with ASD and their family might have.

Inclusion from Special to mainstream school

Some pupils with ASD will have the opportunity to attend mainstream schools or colleges to pursue their strengths or as part of a planned programme leading partial or full inclusion. Preparation and consultation with the individual and their parents will maximise the success of these experiences.

Helpful links and sources of further information:

Links within Wales

- In April 2008, the Welsh Assembly Government published the world's first government action plan for autism and this strategy has led to a local ASD lead being identified within every local

authority area in Wales. You can find out who your local ASD lead is by contacting your local social services dept or by contacting the Welsh Local Government Association (tel 02920 468600). The WLGA is the home for three ASD regional support officers who will also be able to give you the information your require. Make sure you receive by email regular copies of the WLGA ASD Strategic Action Plan newsletter, which updates autism progress and practice throughout Wales, simply give you email address to the WLGA ASD Regional Support officers ASDinfo@wlga.co.uk

• In 2010 The Welsh Assembly Government commissioned an evaluation of ASD children's Assessment and Diagnostic services. Also in Wales from 2010 the new Wales Autism Re search Centre (WARC) was launched and is located in the School of Psychology, Cardiff University. The Director of the autism research team is Professor Sue Leekam, Chair in Autism. The research centre's website is www.cardiff.ac.uk/psych/home2/warc/

• Autism Cymru operates www.awares.org a bi-lingual information site for autism in Wales and this site also hosts the world online autism conference every autumn which includes many of the world's most prominent educators, clinicians, re searchers and practitioners in the field of autism.

Links within Wales

• The National Autistic Society website contains very useful guidance and advice for teachers and lecturers www.nas.org.uk

• All-Wales Autism Resource : a bi-lingual information resource for ASD in Wales and each autumn runs the world on-line autism conference featuring many of the world's leading educators, clinicians, and researchers www.awares.org

• Adam Feinstein, who is a both parent of a young man with autism and is employed in Wales by Autism Cymru, is the author

of "A History of Autism, Conversations with the Pioneers" published by Blackwells/Wiley. This includes the most accurate history to date of autism, the way is currently viewed throughout the world and the approaches being used by governments and those working with people with autism. This book is viewed as a modern 'classic' in the disabilities field

- Autistic Spectrum Disorders in the Early Years (Autistic Spectrum Disorder Support Kit (2006). Authors Lynn Plimley, Maggie Bowen and Hugh Morgan, and published by Sage/PC

- The Autism Inclusion Toolkit: Training Materials and Facilitator Notes (2008). Authors Maggie Bowen and Lynn Plimley. Published by Sage/PCP.

Appendix

Child initiated approaches

What	Where
D.I.R - The Developmental, Individual Difference, Relationship-based (DIR/Floortime) Comprehensive assessment and intervention program to build social, emotional and intellectual capacities rather than focusing on skills and isolated behaviours.	Sessions can take place in the home or any setting.

Who	How
Developed by Dr. Stanley Greenspan, the Clinical Professor of Psychiatry and Pediatrics at George Washington University Medical School. http://www.icdl.com	Encouragement of the child's initiative and purposeful behaviour, through pretend play. Always following the child's lead. Activities are geared to capabilities : motor coordination, sensory, sensory integration, visual-spatial, and perceptual activities. Support aids engagement, attention, and regulates interactions with others.
What	**Where**
The Son Rise (Option) approach. The child receives intensive 1:1 support in a specially modified room, which minimises distractions and makes interacting with the other person in the room the focus.	Home-based, child-centred and carried out by parents and volunteers/ facilitators, trained by the parents. Parents receive training from staff at the Autism Treatment Centre of America. Follow-up support is available. Self-help groups set up around the UK.
Who	**How**
Developed in Massachusetts, USA, by the parents of a severely autistic boy. The Son-Rise Program, Autism Centre of America. www.autismtreatmentcenter.org	Son Rise program based on: • Non-judgemental and caring attitude. • Joining children in their repetitive/ ritualistic behaviours.

	• Teaching socialisation, communication and a love of learning through dynamic interactive play. • Parents are the child's best resource. • Facilitating permanent skill acquisition by capitalising on the child's own motivation.
What	**Where**
Applied Behaviour Analysis (ABA) - methods based on principles of behaviour to build socially useful repertoires and reduce problematic ones.	Initially parents undertake ABA as a home-based early intervention program. Parents hire tutors and have training in ABA to carry out the intervention with a gradual inclusion process into a nearby mainstream placement, if appropriate.
Who	**How**
Dr O.Ivar Lovaas www.lovaas.com www.peach.org.uk	ABA view ASD as a syndrome of behavioural deficits and excesses with a neurological basis, but are nonetheless amenable to change in response to specific, carefully programmed, constructive interactions with the environment. Intensive intervention can be up to 40 hours per week using parents and trained therapists.

What	Where
Early Bird - a three-month programme combining group training sessions for parents & individual home visits with video feedback, helping parents apply what they learn whilst working with their child.	Generally in the home.

Who	How
Jo Stevens, Director, NAS EarlyBird Centre E-mail: earlybird@nas.org.uk	Early Bird programme aims to: • support parents between diagnosis and school placement; • empower parents and help them facilitate their child's social communication and appropriate behaviour within their natural environment; • help parents establish good practice in handling their child at an early age.

What	Where
TEACCH - Treatment and Education of Autistic and related Communication handicapped Children was developed by Eric Schopler at the University of North Carolina in the 1970's.	Most home/school and public settings.

Who	How
www.teacch.com Regular TEACCH training courses are offered by Autism Cymru jennie@autismcymru.org	Partnership with parents is a cornerstone of its philosophy. It looks at the individual in a holistic way. Emphasis is on structure and routine tailored to the individual needs. The use of visual schedules, individual work, prompts and rewards are integral to the approach which can offer 'cradle to grave' support structures.
What	**Where**
PECS- The Picture Exchange Communication System developed by Andrew Bondy and Lori Frost as a method of communicating using pictures or symbols.	In most home, school and public settings.
Who	**How**
www.pecs.org.uk	Six phases encourage children to exchange pictures/symbols for items they want. PECS allows nonverbal children and adults with ASD and other communication deficits to initiate communication. Also recommended for those who have disordered language development to re-learn the meaning of communication.

What	Where
Social stories are personalised stories about a particular social circumstance that needs addressing, emphasising understanding what is needed.	In most home, school and public settings
Who	How
www.thegraycenter.org	A social story is a personalised story that is written for a specific circumstance – whether for guidance, a change of reaction or an affirmation. The story uses the situation as a focus and is written with the child's name or in the third person. The story is presented in a way that will be understood – with pictures/photos/symbols and it can be illustrated. It is used on a regular basis to explain something or pre-empt a negative response.

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