



Llywodraeth Cynulliad Cymru
Welsh Assembly Government

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Autistic Spectrum Disorders

Information for Practitioners who have an
interest in Developing Property or Services for
Housing and / or Day Opportunities

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Who is this Awareness Guide For?

This awareness guide is written for practitioners who have an interest in providing property or services for housing or day services, i.e. service providers, registered social landlords or practitioners involved in property development.

A Brief Description of ASD

For many people with ASD the world can feel very unsafe and confusing – just coping with daily life can be a huge challenge. Having your own home or space can help to improve quality of life, but getting it wrong can cause extreme anxiety and stress. Living in a communal setting, for example, could be extremely difficult for someone with ASD, as sharing space with people they have not chosen to be with can cause discomfort. Also, situations that most people would find tolerable can become unbearable because of extreme sensory sensitivity. However, for some people with ASD, communal living with varying levels of environmental noise and bustle can provide a welcome sense of security and community. Each individual will have different needs and it is important that this is recognised.

ASD is a complex ‘spectrum’ disorder, which includes Asperger Syndrome and affects around 1 in 100 people in very different ways. People on the autism spectrum experience three main areas of difficulty, known as the Triad of Impairments. (Wing L. and Gould J.(1979), Wing, L. (1996).

- Social Interaction – difficulty in social relationships, for example appearing aloof and indifferent to others.
- Social Communication – difficulty with verbal and non-verbal communication, for example not fully understanding the meaning of common gestures, facial expressions or tone of voice.
- Social Imagination – difficulty in the area of imagination and flexibility of thought, for example being interested in a limited range of activities which may be copied or pursued rigidly; difficulty with understanding what others think and feel.

In addition to the triad, people who have ASD may show a resistance to change and experience sensory sensitivity. Many people with an ASD experience either hypersensitivity or hyposensitivity in at least one of the senses (vision, hearing, olfactory, gustatory, proprioception, vestibular and touch). Someone with heightened sensory sensitivity might find noise that other people would not notice intolerable, for example the noise from an electric light or a vacuum cleaner; another person might find that looking at certain patterns or colours on walls causes them distress. They may have problems or anxieties when they feel too hot or when things seem very bright. Meanwhile, someone with reduced sensory sensitivity might not respond quickly to pain, which could leave physical problems to persist or worsen.

People with a diagnosis of Asperger Syndrome share the difficulties with social interaction, social communication, social imagination and their sensory system, but generally have fewer problems with language, often speaking well. Those with Asperger Syndrome also often have average or above average intelligence.

Planning Housing Options

It is good practice for local authorities/areas have available a range of housing options. Some people may need to live alone and would find it hard to tolerate anyone else's company. Others may want daily contact but may need self contained accommodation arranged in clusters where contact with others can be managed. Occasionally people will want to live with others in supported living or residential care options. Good person-centred planning should reveal individuals' preferences and needs.

It is important that local authorities provide an Assessment of Need for Housing and Support by someone who has knowledge of ASD.

Good individual planning is vital as people affected by Autism and their families often need more help, advice and information and, in fact, how that advice and information is given also often needs careful planning.

Housing Options

As with anyone, a change in housing options may be necessary for people with ASD as their needs and desires change, for example from the parental home to supported living, or from a larger to a smaller group home. As people get older, housing needs may also change once again, perhaps taking physical frailties into account, or a wish for a different type of lifestyle. There will need to be a variety of housing options to reflect this, which may include:

Self-contained, individual housing; this could be shared ownership, accommodation which is rented, either from a commercial landlord or a registered social landlord or bought in trust.

Dispersed self-contained housing with support: where a number of self-contained properties are spread over a single geographical area, with one staff team being shared by people in all the properties. Staff do not live in. People being able to provide a 'circle of support' for each other.

Self-contained flats within a cluster; built on one site, including bed-sits and possibly some communal facilities.

Group homes; two or more people living in the same home and sharing facilities. This is the type of service favoured in the past and therefore, for historical reasons, the reality for many people who have an ASD.

Supported living: this is an approach rather than a single type of service. It is built around 5 key principles;

- Housing and support are offered separately. Someone can change the type of support they receive without having to move house, but equally, they can move and still receive the

same support. People have tenancy rights over their own home. The focus is on one person at a time, providing a very individual service.

- People are offered choice about where to live, who to live with, whether to live alone and who supports them.
- It is accepted that even people with complex or multiple disabilities require choice over where they live and who they live with. Therefore, nobody is rejected from a type of service simply because of the complexity of their disability
- Existing relationships with family and friends are respected and developed.

Positive strategies can ONLY be developed by fundamentally understanding how autism affects the individual. This will include a detailed analysis of the person's situation, environment and sensory profile amongst other things, to investigate the functions of any behaviours that may occur that hamper a person's life - it is important to consider whether the behaviour is a problem.

Remember, all behaviour has a purpose although sometimes it can take time to understand.

Housing benefit and Supporting People grants

The following information has been collated from the www.direct.gov.uk website which advises individuals on funding for housing and supported living grants.

Living independently: If a person with ASD lives in their own home there are three main considerations:

- Does the person receive the necessary support to live as independently as possible?
- Do they have the right equipment to help them a daily basis?
- Does their home need adapting in any way?

Individuals with ASD have the right for their needs to be assessed by the social services department of their local council.

Supporting People Grant

‘Supporting People’ is the Welsh Assembly government programme for funding, planning and monitoring housing related support services. Its aim is to improve the quality and effectiveness of the support services at a local level.

Supporting People began on 1 April 2003, bringing together various housing related funding streams. It is a grant programme administered in partnership between Housing, Health, Social Services and Probation, and delivered largely by the voluntary and community sectors, and housing associations. Its main aim was to help end social exclusion by preventing crisis and more costly service intervention and enabling vulnerable people to live independently through the provision of housing-related support services. ‘Supporting People’ only funds housing support but can provide complementary support for people who may also need personal or medical care. This can be part of a package of differently funded, but co-ordinated support which meets the needs of individuals. Supporting People offers support with:

Respite care can take many forms such as:

- debt counseling
- life skills training
- form filling
- advice on paying bills
- provision of emergency alarms

There is more information on the Supporting People website www.spkweb.org.uk

Integrated Community Equipment Services Grant: is a grant to help a person with a disability to buy equipment for their home that will enable them to stay in their home. An occupational therapist will need to carry out an assessment in order for this grant to be accessed. Direct contact 0303 444 0000 contactus@communities.gov.uk

Disability Living Allowance (DLA)

Disability Living Allowance is a tax-free benefit for children and adults who need help with personal care or have walking difficulties because they are 'physically or mentally disabled' including learning disability. (www.direct.gov.uk)

Disability Living allowance can be accessed if:

- The person has a physical or mental disability, or both.
- The person's disability is severe enough that they require support for walking/ getting around and with personal care e.g. washing, dressing, eating, getting to and using the toilet, or communicating needs.
- The person needs supervision to avoid putting themselves or others in substantial danger.
- People need to be under 65 to claim.

People can get Disability Living Allowance whether they work or not. It isn't usually affected by any savings or income that the person has. There are three rates of care component depending on how the disability affects the person:

Lowest rate - if the person needs help or supervision for some of the day or is unable to prepare a cooked main meal.

Middle rate - if the person needs help with personal care frequently or supervision continually throughout the day only, or help with personal care or someone to watch over them during the night only.

Highest rate - if the person needs help or supervision frequently throughout the day and during the night.

People can get Disability Living Allowance for care needs - even if no one is actually giving the care the person needs and even if they live alone.

For all further information a full explanation for all benefits and applications etc. can be accessed on www.Direct.gov.uk
The National Autistic Society has a helpline that will offer information and guidance on benefits: The Autism Helpline (0845 070 4004)

Direct Payments

Direct Payments are available as a right under the amended Direct Payment Act 1996. This means someone with a learning disability could receive cash to arrange their own package of care. There are pros and cons of opting for a Direct Payment. It will usually imply an amount of support to actually administer and account for the payment to employ personal assistants, recruit and supervise personal assistants. This is not consequently likely to be suitable or appeal to everyone. It is however, another route to affording a tailored package of AT.

Individualised Budgets are based on a similar principle as Direct Payments in that the individual has control of how their support is arranged. They differ in that the person is allocated a sum of money for care and support according to a local banding and they have the choice of employing staff directly, or employing one or more care providers and/or purchasing a place in a supported housing scheme. The funds from an Individual Budget can also be used to purchase AT.

Direct Payments are not additional money. The funds used to make payments come from Social Services care budgets. Direct Payments are simply a different way of arranging and delivering care, which give some people and their families greater control over how a package of support and care is provided and who provides care.

Building Design

Each person's needs are very individual and should be assessed properly by someone who understands autism before any design of property or support package is put in place. Occupational Therapists can help in terms of a sensory assessment, but there are also general good practice guidelines that can be adopted and tailored to the individual. The following

is a range of good practice ideas to consider when either developing new build accommodation/property or renovating existing property. In practice a 'new build' project is easier to develop where the accommodation is being developed for very complex needs. The following are some good practice guidelines.

- A low arousal environment; generally individuals who have an ASD seem to prefer living in a non-cluttered, calm and tranquil environment (although there are always exceptions to this).
- Larger spaces: Buildings may need to have larger than average room sizes and larger corridor space to provide this feeling of low arousal.
- A clear layout and organisation of spaces in a building can minimise confusion about location of rooms and their different uses. It may be helpful to keep furniture to the peripheries and the middle of rooms clear. Separating different activities may be important; sitting rooms, quiet rooms, kitchen and bedroom to give clear information about the activity in each room i.e. avoid giving rooms multiple uses.
- Shared living space: careful consideration needs to be given towards the sharing of any space in a home or day activities environment. People with ASD vary in their need to be around other people, but some may find it extremely difficult to be around others, especially in their own living accommodation. Shared living space does not always have to be incorporated in design, but if it is it should be offered as one rather than the only option for living. Alternative living areas, exits and entry areas are always a good idea to offer people the chance to be away from others when they need to.
- Interior design factors; It has been suggested that strong patterns in furnishings should be avoided and colours that distinguish walls, floors and furniture make rooms easier to navigate. Neutral colour to the interior décor, minimal furniture, good sound and echo reducing inclusions such as canvas on the wall and carpet rather than hard flooring can also help towards a low arousal environment. However there may also be a conflicting need to provide hard wearing, durable

surfaces that can withstand wear and tear and be maintained to a good standard. Curtains have been found to be a problem for some. Velcro attachments or blinds (even integral blinds) can be provided as an alternative when problems occur or are anticipated.

- Lighting, Temperature and Sound; are important factors to consider as a feature of ASD can be heightened or reduced sensory sensitivity. This differs between individuals and can be a source of pleasure to some and a source of annoyance to others, and can fluctuate in intensity, sometimes being a mild problem, sometimes being severe. Natural light is good and gives an added sense of space. Reflections, or reflective and glossy surfaces, fluorescent lighting, harsh lighting and shine can be a problem for some people. Softer, coloured lighting is sometimes felt to be calmer. Some people can be over or under aroused by being too hot or too cold and, therefore, some thought might also need to be put into how the temperature of their environments is managed and controlled.
- Serviceable and hardwearing materials; are readily available and many forms and types of materials can be specified or any requirements. Some people with ASD may be overly heavy on their environment or belongings.
- Minimising fixtures, fittings and furnishings; these areas will need to be addressed after assessment and specified to the individual person's needs. If a building is being built from scratch, there is an option to conceal pipes and cables under the floor etc. Under floor heating can be considered where the use of external radiators or exposed pipe work might be assessed as problematic.

Assistive Technology

Assistive Technology is a description for a range of gadgets and technology that can help people to be more independent in their every day lives. Most Assistive Technology is used by elderly people, but there are certain gadgets and systems that can be just as beneficial to people with ASD in the following ways;

- To support an independent lifestyle, especially if there is a new move from a more secure or protected setting (home with parents or institution).
- To provide support in a less intrusive manner.
- Helping in creating a safer environment.
- Prevention of accidents.
- Enabling quality of life.
- Giving greater control to a person with ASD.

Gadgets that have proved particularly beneficial in the past (by individuals with ASD) have been one or more used in conjunction of the following:

- Flood detectors in the bathroom.
- Door alarm systems.
- Bed sensors – especially useful for those with Epilepsy, as night seizure activity can be detected without staff having to continually check that the person is well, causing disturbance to their sleep.
- Door entry – fob systems, that offer ease of access when keys can't be used or are difficult in their usage.

SMART homes; were pioneered by the Joseph Rowntree Foundation and involve putting an array of equipment into a home, such as; door closing and opening systems; Fob access systems; CCTV systems for security and boundary observation all of which can be controlled locally at the home, either by staff or the individual themselves.

For further information, please see the selection of manufacturers below or access the website: Telemedicine Information Service www.tis.bl.uk

Tunstall	www.tunstallgroup.com
BT	www.bt.com/homemonitoring
Attendo	www.attendo.se
Jontek	www.jontek.com
Tynetec	www.tynetec.co.uk
Vivatec	www.vivatec.co.uk
Initial	www.iess.co.uk
Docobo	www.docobo.co.uk
Nestor	www.primecare.uk.net
Huntleigh Healthcare	www.huntleigh-healthcare.com
Carionetics	www.cardionetics.com
SRS	www.srstechology.co.uk

Managing Risk when Developing Environments

Security and risk management also extends to the building design; risk assessments for general management and individual circumstances should inform design decisions. For example there may be a concern about:

- Safe use of equipment and fittings.
- Poor co-ordination and balance.
- The need for assistance with basic personal care.
- The need to control access to areas of the building.
- Occasional deliberate damage.

For many people, their own confidence and ability may be such that close supervision; is not necessary and the aim should always be towards greater choice and autonomy, not control and confinement. The process of risk assessment and plans for risk management should address to what extent physical solutions are needed to reduce risk and where organisational methods are more important, for example by offering more staff support etc.

Security may be part of a duty of care if residents are at risk of running off and getting lost but movement should be managed rather than controlled by physical behaviours as much as possible. Window heights and openings, especially above ground floor, need careful design. Safety needs to be part of design: hard corners, edges, furniture, equipment, wiring, plumbing, heating and electrics, rails and banisters etc.

Supervision and ease of observation are another element of managing the environment and the layout, corridors and doors are important. This has to be balanced with the need for privacy and the use of technology is one way in which supervision can be less intrusive.

A checklist of possible additional requirements is given below but a more detailed discussion can be found in the 2002 RIBA publication. Designing for special needs by Maurice Harker and Nigel King.

Helpful Links and Further Reading

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 appointed 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 you 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

- As a result of the WAG ASD Strategic Action Plan there are a number of other awareness-raising materials being published for Teachers, Police, GP surgeries etc but also very specific materials around housing design for people with autism.

Further Reading:

- Feinstein A (2010) "A History of Autism: Conversations with Pioneers", Blackwells/Wiley. Adam Feinstein, is both a parent of a young man with autism and is employed in Wales by Autism Cymru. His book 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 already viewed as a modern 'classic' in the disabilities field.
- Wing, L. (1996) the Autistic Spectrum: A guide for Parents and Professional. London: Constable. This publication is has been viewed for many years as the definitive introductory text on the subject.
- Harker, M. and King, N. (2002) Designing for special needs. London: Royal Institute of British Architects. This important text is of great value for designers, builders, clerk of works within the wider disabilities field.

Useful Websites

- Association of Social Alarms Providers (ASAP): a membership organisation for telecare and alarms service providers
www.asap-uk.org
- ASTRID Guide www.ASTRIDguide.org
- All-Wales Autism Resource: www.awares.org
- Care & Repair Cymru- General Enquires: 029 2057 6286
Email: enquiries@careandrepair.org.uk
web: www.careandrepair.org.uk
- Centre for Independent Living - www.ncil.org.uk
- Disabled Living Centres Council (DLCC) www.dlcc.org.uk
- Housing Options - Enquires: 0845 456 1497
Email: enquiries@housingoptions.org.uk
- Website: www.housingoptions.org.uk
- Integrating Community Equipment Services (ICES)
www.icesdoh.org
- Learning disabilitywales.org.uk – this is a website that offers a variety of information for people with learning disabilities across Wales.
- National Initiative for Telehealth (NIFTE) Framework of Guidelines www.cst-sct.org
- National Autistic Society; www.nas.org.uk
- Ricability www.ricability.org.uk
- Social Alarm and Telecare Association (SATA)
www.sata-uk.org.uk
- Smart Homes databases www.rethinkhousebuilding.org
- Supporting People website www.spkweb.org.uk
- Telemedicine Information Service www.tis.bl.uk – including supplier database, project listings and organisations.
- Division TEACCH -CB 7180, 310 Medical School Wing E, The University of North Carolina at Chapel Hill, Chapel Hill, North Carolina, 27599-7180, USA tel: + 1 919 966 2174
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