

Accommodation and Asperger Syndrome

Safe and appropriate accommodation is an essential and significant need for everybody, but far more so for a person with AS (Asperger Syndrome).

Due to the social and interactive difficulties inherent in the condition, an appropriate home may be the single most significant aspect in the life of a person with Asperger syndrome. Spending time with family and friends, or in familiar places, may be large part of most of our lives, a person with AS may need or choose spend most of their life at home alone, people with AS also find significant changes terrifying and debilitating in the long term. The ability of a person with AS to function at all often depends upon a combination of a safe and appropriate home and long term security.

Homelessness, inappropriate housing or insecure accommodation can be intolerable to a person with AS to the extent of a significant risk of suicide developing within a relatively short period of time. In very real terms, to leave a person with AS homeless, or without an appropriate home is to place their life at risk.

So what is an appropriate home for a person with AS?

We created a survey to try and identify and define this. Interested parties with, and without, AS were invited to make anonymous submissions to our survey both online and manually.

We asked people with AS about their current accommodation and their views of various different types of housing and localities. We also asked people with and without AS to express their views on the current accommodation of a person they knew well with AS and their views on the suitability of various types of housing for people with AS in general.

We discovered, overall, that there are no hard and fast rules. The, self reported, accommodation needs of adults with Aspergers syndrome are as diverse as the accommodation needs of any other social group. However patterns of special needs did emerge.

The most important of those needs was the need of adults with AS to be consulted on their own behalf. There was a huge discrepancy in the way that interested parties felt Adults with AS would respond to certain types of housing, and the way that adults with AS actually felt.

For instance, the majority of Adults with AS felt that sharing a home, or sheltered accommodation would be intolerable, and yet the majority of interested parties felt that Adults with AS would find a shared home or sheltered accommodation anywhere between tolerable temporarily and ideal.

Sheltered Housing

There were, however, notable exceptions among the adults with AS, who, whilst being adverse to sharing a home with others, on any terms, suggested:

- *" ... a 'warden' on duty every day 24 hours a day. So if there are any problems, whether it is something like a neighbour being noisy and you would like the warden to politely ask them to turn the noise down, or whether it is something more serious like if a person is ill and needs first aid or an ambulance.*

It is also useful if there are problems with misunderstandings and communication and social problems - the warden can act as an impartial mediator to resolve such confusions and to deal with people misbehaving too.

In addition, individual residents can have extra support as required - some people may need 24 hour support from a carer, others may just need someone to visit them once a week to make sure they are coping okay - and if there are any problems in-between visits, the warden will always be there to help...."

- *"There should be help available for dealing with bills, food, cooking, money, looking after oneself, dealing with 'conflict', dealing with social issues, what to do when something goes wrong or breaks in the house - ideally some kind of free advice service or advice worker should be available 24 hours a day (either at reception or in an office but easily contactable by phone)"*

This idea moves towards the idea of a warden as a non-invasive "advocate" rather than "custodian", which might find more merit among adults with AS (or, indeed, other disabled people) than more conventional models. This comment takes that idea one, very practical, and useful, step further:

- *"I would often feel that I lack the organizational skills needed sequence the tasks involved in gaining accommodation. Even ringing strangers is scary for me. For these reasons it may be beneficial that a person with Asperger's has someone who will advocate for them when they look for a place to live."*

It is often said that people with AS do not so much have difficulty coping, as difficulty in finding a path to the life situations they should be coping with in order to lead full, useful and fulfilling lives.

Integration

Questioned informally, young people with AS showed considerable insight into the needs of other young, disabled people, as well as their own needs, and felt that, within sheltered housing, an integrated environment of mixed disabilities would be more acceptable than an "AS ghetto". They did not

feel that integration with elderly people would be appropriate or successful for anyone concerned and expressed concern that other young, disabled people may have been so accommodated in the past.

Education for Change

The prospect of change causes people with AS to suffer extreme anxiety. Young people are sometimes afraid to leave their family home for the first time even when they find it intolerable to stay.

Discussion suggested that the established need for "respite care" could be utilized in an exciting new way as an education for independence, and an opportunity to give young people with AS a chance to become accustomed to living an autonomous, adult life.

Special Interests and Aversions

People with AS often develop special interests and aversions and several people expressed concern that this must be taken into account in developing appropriate accommodation. It is not unusual for a special interest, or even a pet, to have the same emotional significance as a child or spouse for a person with AS. Conversely, an "aversion" would be akin to a phobia and represent an ongoing disruption to both health and functionality, significantly exacerbating the level of disability experienced by a person with AS in very real terms.

- *"...Pets that won't be a nuisance to others (i.e. pets that won't be noisy) should be allowed in sheltered housing..."*
- *"...my little dogs are my family. I wouldn't want to live at all without them..."*
- *"personally I have severe problems with electricity in the house and would prefer to live without it"*
- *"in my case it's very necessary to live near the ocean."*
- *"...a person with Asperger's was given accommodation in the centre of a village next to a noisy main road. He often complained about the noise of cars outside his house, to the point that he was prosecuted for wasting Garda time (he was given 3 months probation for ringing the Gardai 29 times in 1 hour). This would not have happened if the idiots who arrange his housing accommodation understood his sensory sensitivities and gave him a place to live that was quiet..."*
- *"Accommodation must also be QUIET as many people on the spectrum have very sensitive senses and have sensory overload as the world is a very noisy place!"*
- *"It would also be useful if each flat had double glazed windows and some sound proofing (although not too much - someone still needs*

to be able to make themselves heard if they need to call for help) and also individual temperature control in each flat in order to cope with the varying sensory integration issues (hypersensitivity or hyposensitivity) that people with ASDs have."

Personal space, Autonomy and Sanctuary

The greatest, most significant need of all, expressed over and over, was the need for personal space, autonomy and sanctuary from a world that causes adults with AS a myriad of constant, involuntary and inevitable stresses:

- *"The need for having own space is very real. It is also difficult to assert to other people for someone with AS."*
- *"Noise too can be horribly distressing and simply being surrounded by people can be unbearable. In years gone by the local authorities in Ireland built cottages complete with around an acre of ground. They only had 4 rooms and no bathroom but I feel that something like this would be ideal. They were usually built in fairly remote locations. It does strike me that if it was possible then it must be possible now. I guess it all comes down to money."*
- *"I couldn't survive near other people; I would never be able to relax for a single moment. I would rather die."*
- *"The council here has recently decided that they intend to inspect all homes on a regular basis. This has had a majorly negative effect on my feelings about living in this house. I have territory and invasion issues, these are real and serious. Councils need to consider people like me before deciding on this kind of policy. It's insensitive and uncaring."*
- *"Must be quiet with adequate but not over-zealous support available (if required). Must be as self-contained as possible so as not to 'force' interaction for those who do not want it or have difficulty coping with it."*
- *"My ideal housing would be to live on my own"*

A person with AS will usually live most of their life in their home. They have more chance of being self supporting if they can work from home, most of their leisure activities will take place at home. They need separate living space, work space, storage space and sleeping space. Many have additional issues akin to claustrophobia.

A studio or single bedroomed apartment is unlikely to meet the needs of a person with AS adequately, and being limited to such would significantly impair quality of life in most cases

Bullying

Adults with AS also attract bullying, while lacking the social skills to have any hope of resolving or coping with it:

- *"It needs to be ensured that people on the spectrum are protected from bullying and any 'enforced' socialising."*
- *"Protection from bullying by people who live nearby and also on public transport that people on the spectrum use to get them to work or into town etc."*

Medical Issues

The issue of medical care being tied to location was raised more than once. It would seem that lack of flexibility in the choice of GP by location may be inhibiting the accommodation options of the individual. As most disabled people have special, long term, medical needs similar factors may well apply:

- *"People on the spectrum should be able to choose whatever doctor they like rather than have this dictated to them by their locations as many doctors don't understand AS/HFA and also it can be upsetting for someone to see a doctor who doesn't understand or to have to change doctors at all."*
- *"I am afraid to move from this area in case I could not find a new Doctor I could be comfortable with, who understands AS. Too many GPs think that AS is a self esteem issue that can be fixed with pills and reinforcement, with the same disastrous results as vodka. Or that if you are cornered enough, by taking away your supports, you will suddenly start thinking and reacting like a normal person. Of course you can't. So that their wonderful strategy leaves you high and dry. Sometimes without even the basic means of survival."*

Choice, Choice, and Choice

Across the board adults with AS, and others were united in feeling that accommodation must be tailored to individual needs, not only for people with AS, but for all persons with disabilities:

- *"Obviously different disabilities have different needs but if these needs are recognised and guidelines given then it would be a simple process of making the necessary adaptations dependent on the disability of the individual."*
- *"There's a big need to be asked what is needed and for assumptions never to be made for those with disabilities."*
- *"People with Asperger syndrome and HFA are all unique. They may share issues but all have their own individual perception of the world. Therefore I believe that it is crucial for there to be individual consultations made when considering the provision of housing"*

- *"I believe that people are entitled to have their personal desires taken into account when housing is considered. I do NOT believe that a diagnosis of a difference from an arbitrary 'norm' entitles authorities to assign a particular lifestyle to any individual, but that, as a caring society, we should provide everything necessary to remove barriers to people achieving their personal goals."*
- *"Housing accommodation should meet the individual needs of the person. Everyone should have a right to choose the type of accommodation that meets their needs whether it is to live independently in an apartment or to live with parents."*
- *"Choice is the ideal! Being able to choose what you need."*
- *"Ask the individuals concerned!"*
- *"I think it depends on the person"*

The Final Solution

Tailoring accommodation to the individual needs of every disabled person in the country is a daunting prospect. The results of the survey did, however show one possible alternative.

Every single person who answered would find owning their own home at least "tolerable in the long term"; by far the greatest majority would that option "ideal".

The 19,000 disabled people assessed nationally as having "long term housing needs" (2006 figures), will probably never be able to purchase their own homes. For the state to continue to pay out rent to private landlords whether in rent supplements, or in the terms of the rented accommodation scheme is a cost, "dead money", often for insecure and inadequate housing that falls very far short of meeting those individual needs.

What if the state were to purchase homes on behalf of individuals with disabilities giving them a budget within which they could select their own homes on the open market that they could then rent back in terms similar to existing social housing? With an option to buy should that ever become possible.

This may sound utopian, but, in the long term, it would save a great deal of money, being not so much a cost, as an automatically index-linked, capital, investment that would lead the world in terms of meeting the accommodation needs of disabled people.

There would be additional benefits in terms of spontaneously randomising the social housing stock and moving further away from the social housing ghettos that have consistently proved to be sociologically undesirable.

We need to recognise that all disabled people need real, secure, homes for life that recognise all their social and emotional needs and potential.