



SCOTTISH AUTISM SERVICE NETWORK

# **An Ordinary Life**

Perspectives on living life to the full  
The needs, rights and aspirations of  
people with Aspergers

Scottish Autism Service Network  
Asperger Forum  
2011



### Acknowledgements

This publication is the result of a lot of discussion and hard work by the members of the Scottish Autism Service Network Asperger Forum. This group meets regularly to debate and discuss issues that matter to people with Asperger Syndrome. Members of the Forum each have a diagnosis or recognise themselves as someone with Aspergers. The group is currently facilitated by Aline-Wendy Dunlop and Maura Lynch: currently Project Developer for the SASN Adult Autism Health and Wellbeing Project. We owe a debt of gratitude to Dawn Larman who originally recognised the potential of such meetings, Gill West who worked as the Project Developer until April 2011 and Charlene Tait whose idea inspired this writing project.

The Writing Group is made up of members of the Forum, with contributions from their invitees from Edinburgh and Lothian Asperger's Society and Autism Rights Group Highland and associated professionals who were invited by the Forum members to take part. All concerned gave their time, knowledge and enthusiasm freely. We hope that 'An Ordinary Life' will contribute to a wider understanding of inclusion-exclusion issues for people on the Spectrum, as well as giving a shared voice to people with AS and professionals on a range of relevant topics generated through personal experience and group discussion. We consulted more widely on these topics and would like to thank all those who took time to share their views with us. We have drawn on their contributions too. The cameos are drawn from life but are sometimes composites rather than individual experiences – in this way we hoped to represent life with AS: these and all direct quotes from people with AS are shown in italics.

Whilst the work draws on personal experience it aims to take powerful individual and collective experiences and present them in a way that recognises that such experiences affect people well beyond our particular group: we have therefore aimed to generalise and for this reason we have anonymised the scenarios and personal voices of all involved whilst retaining a collective voice.

We include in our contributors list all those who expressed a wish to have their contribution acknowledged. Thank you all: this is your publication.



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### Overview

The Scottish Autism Services Network was originally developed through grant from Scottish Government with the express purpose of providing a modest professional network for those working in the field of autism in Scotland. From the start individuals with autism, their families, carers and the professionals who worked with them were consulted about what such a network should aim to achieve and to what benefit.

As a result a strong values base was developed. This declared the inclusive but impartial nature of the Scottish Autism Service Network (SASN). Membership involves signing up to a set of principles and gives access to the web based information hub: highlighting events, services, and policy, practice and research. A regular SASN newsletter is offered too. A number of topic focused Networks were developed including employment, commissioning, clinical issues, education, transitions and the SHARP group. Geographical and professional networks also developed. From its inception the SASN Development Group included professionals, individuals on the autism spectrum and parents and family members.

Whilst parents and carers are often members of autism societies and associations, a real gap emerged for individuals with autism and so the SASN Asperger Forum began: the group meets at the University and is facilitated by SASN staff and volunteers. Members come from all over Greater Glasgow, travel from Edinburgh and Fife and keep in touch with members of further flung Asperger groups. The group meets on a regular basis to enjoy discussion, share issues, keep up to date with policy and have a social time together. The regular social contact in a group of this kind allows everyone to have a say and aspirations are often discussed, leading to some key themes which we return to frequently in our conversations and which form the basis of this publication.

Our current project is the Adult Autism Health and Wellbeing Project: a small short term project funded by Scottish Government to look at wellbeing, inclusion and health inequalities for people on the autism spectrum. The members of the Asperger Forum are represented on the Steering Group of this project and have offered valuable advice during the course of this particular project.

Group meetings have provided a forum for project development and had led to a very broad concept of health, wellbeing and social inclusion. The recurring themes have shaped this publication and it is well understood that all of our topics affect individual quality of life: they are health and wellbeing; relationships and family life; education and training; transitions into adult life; employment; leisure and wellbeing; community access and inclusion; housing and accommodation; rights and benefits; growing older and virtual technological worlds. Individual experience varies widely, but these are common themes that shape contemporary life.

Each chapter addresses one of the identified themes of our regular discussions and in each case chapters are a collaboration. We have tried to bring together relevant professional expertise and first hand life experience of living on the autism spectrum. Chapters start with two cameos drawn from experience. In many chapters we refer to relevant literature and make use of project meeting discussions and feedback received. All chapters have an underlying thread which respects the rights, social

inclusion, emotional wellbeing, physical wellbeing, material wellbeing, interpersonal relations, personal development and self determination of people with autism.

The work of the SASN Asperger Forum group has resulted in a publication which aims to give voice - only one of the members was diagnosed in childhood, the others were diagnosed between the ages of 17 and 67. The experience of working together at the Forum meetings has been rich and the contributions have been wide ranging - the communication from people with AS in this group is so powerful and clear and the working process is an education for us all. Not all topics stimulated the same level of discussion and in the future we hope to expand the briefer chapters. Even so it is not possible to include everyone's comments on every subject but we hope there is enough here to give a sample of the everyday issues facing individuals on the spectrum and in so doing to represent their views.

We are all pleased to present the outcomes of this shared journey.



### Chapter 1 - A Good Start to Life

“The true measure of a nation’s standing is how well it attends to its children – their health and safety, their material security, their education and socialization, and their sense of being loved, valued, and included in the families and societies into which they are born”.

UNICEF (2007)

Whilst ‘An Ordinary Life’ focuses on the adult experience, as a group we have reflected on childhood experience as well. With only one of our members having a childhood diagnosis, most of the group feel they missed out on the kinds of help that appear to be available to children with autism now. Greater recognition of autism appears to lead to children being encouraged ‘*to maximise their potential despite not meeting developmental milestones*’, however early diagnosis was thought to mean ‘*your identity is autistic*’ – for some this is a positive, for others ‘*growing up in blissful ignorance*’ might be preferable. Low self esteem, a lack of confidence in others, missed opportunities and not being valued for who you are lead to a number of observations about a good start:

*I think it may help nowadays if children are screened at a young age for early intervention but it will only be in years to come that findings will back this up or not.*

*I think the current changes being introduced to cater for ASC people need to be monitored to see scientifically if in twenty years they have helped.*

*I would like to think that today's children with AS have a little more support with transitions into adult life because that period of life makes you what you are.*

The expectations of others, what others say about you, and what others encourage you to do are all part of childhood. Looking back many of the group recall being interested in facts, pursuing knowledge but also ‘being left behind’.

*Right from early childhood I was always much more interested in “things” than in people. I saw people as just a means to finding out about things and for pursuing my insatiable curiosity.*

*Reading adult science books at 5, 6, and 7 and learning the universe in my own free time, at my own pace of absorption, without homework or tests, without teachers butting in and deciding what was best.*

*Being one of the best in my class at arts and crafts made me feel that I was an equal in the class and also gave me a glimpse of how others must feel most of the time. Wish the teachers had encouraged me with that instead of sneering.*

*A good start might have provided moral armament - knowing how to deal with crooks, cranks charlatans and people in authority.*

*I ended up in a "young people's unit" at 14, with a stress collapse including catatonic unresponsive states, even with which it had been a fight to get removed from impossible schoolwork pressure. I needed from the unit: a gentle refuge from pressure, a place of freedom to develop, a quiet healing time, child protection action against my school, and doctors' backing that its methods were harmful and must be removed from my life allowing me to rebuild my own future, thus saving my child authorship and just maybe my university chances. None of this happened at all.*

As adults we can all reflect on what childhood might have been. The sense of isolation that autism can impose, in some cases the feeling that even your parents wished you were someone else, and the explanation of the past that a diagnosis may eventually bring, are each part of the group's experience. There is widespread recognition that early diagnosis and effective interventions are much more beneficial for both the individual and the family. There remains however an increasing number of adults of all ages seeking a formal diagnosis on the autism spectrum, or seeking reassessment where they feel an earlier diagnosis is incorrect or damaging.

### Chapter 2 - Health and Wellbeing:

The root of health and wellbeing lies in trust in others, confidence, a good sense of self and positive attitudes and dispositions. For people with Asperger's it is important to be seen as "competent, capable, different not disabled" (Brown, 2010), and not as '*broken or defective*'. At the same time life as a person with autism can be intense, stressful and provoke anxiety. This chapter on health and well-being focuses in the main upon diagnosis as for many it has opened a door to a better life. However diagnosis is a risky business and can come about in adulthood through self-recognition: how does an individual ensure a safe experience of diagnosis? Some members of the SASN Asperger Forum attended Asperger groups as a lead into diagnosis, finding that meeting others with diagnoses helped their own journey. This mutual support is often found by joining a group where it is safe to divulge how you are: however too often people with Asperger's find it risky to disclose their diagnosis amongst friends or in the workplace for fear of the consequences.

As we reflected together on health and wellbeing, the suggestion was made that a glossary of unacceptable words, such as 'impairment' could be helpful,

Anxiety and sensory overload do make some activities difficult, for example hospital appointments or procedures. Aspergers can be invisible and competence can result in little support because problems aren't always obvious, however often typical communications do not take account of the fact that the person with Asperger's best way of communicating may be different. A fear of the mental health system and professional interpretation of anxiety and sensory issues as illness, also makes individuals avoid disclosure.

*When I'm upset about something people need to realise it is urgent. I probably feel things more intensely than they would.*

*The need for recognition/ realisation that often what presents outwardly does not (fully) reflect the emotion/ feeling, experienced by the individual.*

*The impact of the views of others can be underestimated.*

### Diagnosis

We discuss some of the issues surrounding diagnosis of Asperger syndrome in adults including the negative and positive aspects as well as implications for the individual. Reference will be made to personal experiences that provide powerful and poignant insights.

No accurate figures exist for the number of adults who are living with autism. The generally accepted prevalence figure is 1:100 of the general population (Baird 2006). Nowadays a significant number of individuals with autism will receive their diagnosis in childhood through a variety of routes including paediatric services or child and adolescent psychiatry. There is no doubt that public and professional recognition of the autism spectrum has improved however many individuals remain undiagnosed or mis-diagnosed.

### **Cameo 1**

*An adult describes her experience of psychiatric in-patient care as a young adult with acute anxiety, and almost complete social withdrawal. Her time as an inpatient was a frightening negative experience where she perceived a lack of willingness amongst staff to understand her reasons for certain behaviours. The expectation was on the individual to make changes to her behaviour and treatment included medication (ultimately ineffective) and group therapy sessions (wholly inappropriate). Overall this period of her life was deeply traumatic and has resulted in a longstanding mistrust of mental health services.*

This cameo could readily be an individual yet to be formally identified as on the autism spectrum and for whom the correct diagnosis had the potential to significantly improve all aspects of her care, and consequently her life.

Individuals seek a diagnosis for a variety of reasons. This may include recognition of their 'social differences' or perhaps particular mental health issues or problematic life experiences. It may be finding and relating to the Asperger scene. It may also represent a desire to feel in a stronger position to access services or in just simply being better understood.

### **Cameo 2**

*It helps to have an explanation of why things feel the way they do, why I do what I do. That makes it a bit easier to cope and you can't start to put right what you don't understand.*

Diagnostic pathways for adults are frequently ill defined, difficult to access or non-existent in many areas resulting in inequalities of care across Scotland. If accessed through a GP are they sufficiently knowledgeable about the autism spectrum or do they decline to refer for a diagnostic assessment based on a superficial understanding of the complex presentations of this condition? Many adults will have had some success at developing social skills that mask the condition and this may be a particular issue for women on the spectrum seeking a diagnosis. Will the GP look beyond the 'labels' an individual may have gathered such as hyperactive, highly anxious, anti social, difficult or uncommunicative and recognise there could be an unaddressed core problem?

If a diagnosis is accessed through mental health services individuals can feel very uncomfortable and indeed fearful especially if they have had a negative experience in the past.

*They have so much power and they would use it....it leaves you powerless.*

Asperger syndrome is a neuro-developmental condition and not a mental illness. Diagnostic services for adults commonly sit within mental health services where treatment expectations are often focused on changing behaviours in the individual. Is this an appropriate or acceptable way to treat people with autism? What does this approach do for their mental wellbeing? Will this focus reduce the individual's feeling of isolation or improve their self-esteem?

*These kind of 'change' agendas violate civil liberties and are often biologically wrong for those with autism.*

Numerous personal accounts written by people on the autism spectrum clearly state

that autism is their way of 'being' and they cannot (and many have no wish to) become neurotypical. They are who they are and look for, and should receive, recognition and acceptance of their differences.

*I now know for certain that I'm different, it's not just my imagination, and neither am I a complete freak. So instead of worrying about my differences and trying to do the impossible and conform, I can concentrate on making the strengths in my differences work to maximum advantage and investigate workarounds for the weaknesses. My diagnosis opens the door to making contacts with other Aspies, communicating and sharing issues with them. I feel I now belong to something, whereas before I was only an oddity.*

There are significant barriers to be overcome by those seeking a diagnosis. Some of the barriers are inherent to Asperger syndrome and include idiosyncratic social development, sensory overload, increased anxiety levels and individual communication differences.

Many of the barriers however can relate to the systems developed to manage various public and health services which include inflexible, and at times, discriminatory practices.

*How do you establish in advance, and from an undiagnosed position, that you will be accepted as mentally healthy and survive the contact with that system...?*

Professionals need to be aware of the challenges faced by people on the spectrum and offer appropriate and accessible information and support on issues such as finances, housing, employment and relationships. Individuals will need gentle help and guidance to reach a degree of understanding of their autism however the focus should be on skills, abilities and positive qualities such as honesty, reliability and fairness and not on the negative aspects of a diagnosis. Professionals also need to be mindful of the use of defining clinical terminology as it may be difficult for some people to recognise and identify themselves in that way.

It is unkind and unprofessional to give someone a diagnosis of such a pervasive life long condition without provision of some level of aftercare.

*Diagnosis alone is no use, you need a mentor service to go to when you need or text/email when you need, diagnosis can be good with enabling support but leave you different but isolated if no where to go to discuss confusions in daily life a lot of present services are a 'do for' service rather than 'do with' or enable.*

There does need to be recognition of the inadequacy of knowledge and understanding of the autism spectrum that prevails across all services and professions (MacKay and Dunlop. 2004). This increasingly is being met with a professional willingness to improve such gaps but there is some way to go to provide a comprehensive service.

Personal accounts have highlighted the importance of receiving a diagnosis and the positive impact it can have (Lawson, 2001. Williams, 1996). It can change a life.

*A diagnosis has made a massive difference in my life....It gives me a justification and an explanation of life.... I no longer feel adrift.*

For people who have lived their life feeling an 'outsider' the importance of belonging to the Asperger community, before and after diagnosis, cannot be underestimated. It may be the first time they have felt accepted, understood and valued. People on the spectrum wish an ethical and democratic autism community which enables them to organise and communicate amongst themselves. This community can provide support, information and also give a sense of positive regard. There will also be a number of individuals who will have no desire to access such supports.

Recognition also must be given to the potential impact of the forthcoming publication of DSM-V in 2012 where the various subtypes of autism (including Asperger Syndrome) will be subsumed in the term 'autism spectrum disorder' (Szatmari, P. 2011). What will this mean to those who identify closely with the Asperger community? The term 'disorder' is one that many find offensive.

Clearly they may be many fears and anxieties over this loss of their (newly found) identity therefore it is vital that this Asperger community have a voice. Will access to services be better or worse? Will this change make the diagnostic process easier? Can those with Asperger syndrome readily identify with people with autism? How can we best ensure we listen to, and recognise their views, concerns, hopes, and aspirations?

Does having a diagnosis improve well being? *It answered a lot of questions for me and proved I was not going insane. It also helped me retain employment when I might have lost it.*

*It is empowering to have a diagnosis. It allows you the choice of telling people if you wish them to know, but being able to do so with confidence. It also helps to explain many of the painful experiences that you may have gone through thinking that you are to blame and that you need to change to be accepted, rather than society needs to change to understand and embrace those who do not easily fit into the mainstream of society. An assessment/diagnosis should be an automatic right for every individual who chooses to seek one, but the right not to seek one should also be respected and those who choose not to seek diagnosis should be respected. I accept that the latter can cause distress and upset for families and carers, but I strongly believe that the rights of the individual are paramount.*

### Summary

Diagnosing a person on the autism spectrum can be fraught with complexities given the diversity and subtleties of presentation and the overlap with other conditions. Because this process can be difficult does not mean it shouldn't be addressed. There also needs to be a much more coordinated approach to post diagnostic services and care.

### Reflective questions

- In the introductory cameo do you recognise any aspects of the young adult's psychiatric care? What, other than a diagnosis, could have improved this situation?
- What are the recognised routes for adults seeking a diagnostic assessment in your area? How can individuals be helped through these complex processes?
- How can we ensure people with Asperger syndrome feel included and listened to in an understanding and empathetic way?

### Chapter 3 - Relationships and Family Life

Friendships, social interaction, family supports, family traits, sexuality, intimacy, relationships.

*My immediate and extended family now make allowances for me and do not simply think I am being a pig headed, selfish idiot. It has also helped repair my marriage as my wife does not take actions or comments too personally now and can talk straight back to me if I am being out of line.*

*My issues have caused me to be completely isolated from family contacts so I'm on my own and diagnosis hasn't altered that.*

*I had spent a lifetime hiding my feelings and behaviour from my family, work colleagues, and anyone else that I came into contact with and this meant that I had become accustomed to living a double life and suppressing, or even denying, my natural feelings and behaviour. Expressing honest feelings was difficult as my life experience was simply that this always resulted in humiliation by, and further alienation from, those in mainstream society.*

*I simply don't have the social skills to develop close friendships and that leaves me feeling isolated and alienated. The few people that I have had who could be called friends have been scattered throughout my life, but even with these people I never felt a particular level of closeness, so when these friendships ended I didn't feel any great sense of loss. Girlfriends have been even fewer and further between and the longest relationship I have ever had can't have been more than 6 months long. In reality there is a strong possibility that I will not have another relationship with a woman in my life, and I find this deeply depressing.*

### Introduction

It is well documented that people with Asperger's Syndrome (AS) find social interaction challenging, anxiety provoking and fraught with experiences that can dent self esteem. (Attwood, 1998. Nichols, Morvarick and Tentenbaum, 2009. Roth, 2010).

Nonetheless there is often a strong desire to have the same range of relationships that the typical population enjoys. Across the lifespan the number and type of relationships we have tends to grow. The function of relationships change and we become increasingly aware of the shared responsibility we have to make friendships, family and intimate relationships work.

*You feel empty unless you have an extreme reason for feeling, that can be good in intimate relationships but it is horrible to want to feel something for people closely related and not know what to feel or how to bring the feeling up to 'show' or feel awkward because if you state the feeling or pretend show to make them feel good it feels very false to you so you feel more empty.*

As one example, consider the change in relationship dynamics from the wholly dependent new born through to the rebellious teenager who increasingly seeks to assert their individuality and independence. Such change is usual and to be

expected but to achieve it we need to develop a very strong sense of our own identity whilst developing what is ultimately a fairly sophisticated understanding of other people.

Individuals with AS find both self insight and insight into others challenging. The result of this lack of insight can often be perceived as a lack of regard for the other party's feelings, belief, desires or needs. By talking to and engaging with people with AS it is clear that a lack of understanding is not synonymous with not 'caring' about people but rather a lack of inherent capacity to know or sense these things. There is very often the misconception that individuals on the spectrum do not have 'regard' for other people.

This section will explore these and other issues that impact on friendships, family relationships and intimate personal relationships. Reference will be made to personal experiences in this area. The attitudes that professionals can adopt to support people with AS in their various relationships with others will be discussed.

### **Personal and Professional Perspectives**

People with AS may not admit openly that they desire friendships and relationships. They may not even admit it to themselves as it is perhaps too painful. It may be easier to deal with if they just believe that they do not want to mix rather than admit they are not able to form and maintain relationships. The celebrity culture that is evident in contemporary society can often result in people feeling and believing that that the more popular you are, the more worthwhile you are. To admit openly that one has no or few friends may add or enhance feelings of worthlessness. There may be a concerted effort and tendency to channel one's energies into what one is relatively successful at and gain positive feedback/reinforcement from that rather than social relationships which may repeatedly lead to a slap in the face – emotionally....or literally.

Furthermore, it is important to encourage and reassure people that although they do have difficulty with relationships – they are not categorically unable or inept. A fear is that over time, due to negative experiences, people become of the opinion that they have no hope of any sort of 'normal' relationships. Or even as a result of the AS label they assume that they are incapable. This may be the case especially if a person is prone to thinking in quite a black and white manner and does not fully appreciate that there are varying degrees of difficulty in social relationships amongst those on the spectrum.

*The simple fact that I'm more comfortable alone, even working. I feel that there is some kind of "mental block" which affects me greatly in socialising. Small talks appears to be the worst time, and discussing work and interests is more easier.*

These issues signal that professionals need to carefully consider how they impart information to people, particularly those who are newly diagnosed. It can be challenging to be confronted with what is, necessarily, generalised material. It can often be challenging for a person with AS to see themselves reflected in academic and other material that describes AS and other spectrum conditions. Professionals need to be mindful to support and guide people to an understanding of their own identity, capacities, skills and challenges rather than leaving people feeling that all possible permutations of AS will one day impact on them.



People with AS may have been so hurt and rejected in the past by people that they may fear reaching out and being hurt again. It may often be the case that people 'retreat into their shell' as a self preservation strategy - the old adage of once bitten, twice shy but rather repeatedly bitten, forever shy. It is important to emphasize that there are qualities associated with AS which are desirable within relationships – such as honesty, loyalty, tenacity, perseverance and reliability. And it may also be vital to repeatedly point out that the mainstream population gets it wrong too.

This last point is especially important. It is all too easy for the person with AS to own the responsibility for the inevitable breakdowns that occur in a range of relationships. This can render people very vulnerable and results in an inherent inequality in their relationships. Just as there is a need to support people to understand their AS there is also a need to enable people to decode the behaviours, motivations and intentions of their typical peers. This is particularly relevant to developing and supporting good self esteem and a positive self image.

The position and role of the person on the spectrum is significant in terms of family dynamics. Whether the person is the partner, the parent, the offspring or the sibling there is an impact on the dynamics of the family and the expectations placed on that individual.

*I need to protect my family from the knowledge that some of them are also on the spectrum. They don't want to know and could not bear the knowledge.*

Professionals engaging with families need to be mindful of the potential for disruption to family dynamics and to take care not to make assumptions. People with AS are sensitive to this and articulate their experiences and views on this in a variety of ways. Some individuals feel that relationship and family issues arise as the result of the dominance of "neurotypical" culture. That is to say a lack of adjustment or an inability to take account of the unique world view of those on the spectrum – namely their difficulties 'factoring in' other people's perspectives and requirements and even if these are made known to them then they can lack the mental flexibility to accommodate them.

*Seeing things differently. Needing things a certain way. Not understanding others etc has put a huge strain on most of my relationships. It is impossible to communicate just how much.*

It is important to emphasise the value of routine and structure. By keeping as many things as constant as possible it will mean less stress when it comes to the 'variables' which inevitably occur in life. For example, the need to have a set structure for getting everyone out of the house on time in the morning. It may be better to have a set routine of doing things – times into the bathroom etc as AS family members may not be able to foresee and anticipate the requirements and intentions of the other members either because they are unable to predict these needs and/or have the mental flexibility to work around them sufficiently. Stress and confrontation seem to be minimised if constants can be maximised and variables minimised – although clearly structure does not account for all eventualities and indeed can be very boring – particularly for the non AS family members.

It is important to stress that despite appearances the AS member(s) may not just be being selfish and blatantly disregarding the needs of others although it very often

looks this way. Being constantly accused of this is likely to be very damaging to the person on the spectrum's confidence. Not that one seeks to abnegate the idea that people with autism are incapable of selfishness, far from it, but it is important to bear in mind that actions and behaviour are far more often misinterpreted/misunderstood than within the general population.

For others they sense a degree of "overprotection" from families that can make it difficult for their families to anticipate, accommodate or even expect change in the individual. The response of family members on the spectrum is a critical one in terms of building and maintaining self esteem but also that individual's position within the family. Some people express a feeling of inequality, of losing their place in the family

It is highly probable that the individual on the spectrum will require to be told what is expected of them in their role. This is likely to be because they do not intuitively or innately know what is expected in a given scenario and what it would mean emotionally to the others involved. This lack of knowledge and inherent understanding is likely to stem from exactly that: a lack of knowledge and understanding - as opposed to their being indifferent, or even opposed to the feelings of the other individual(s) involved.

For example, consider a son asking his father to attend his football match. The father may need to be told explicitly that his attendance would be highly appreciated in terms of emotional value and support as 'dad'. Without this 'enlightenment' the father may just assume that since the mother is there he is not required. This may be seen as logic failing to capture emotion. Or a wife on the spectrum may fail to understand what it would mean to her husband to attend a work function with him. She may just think he has mates and colleagues there, therefore no need for her to attend, when in fact all most all of the other partners will be there and it would mean a lot to him for them to share the event together.

*I have never felt close to anyone in my family. As a child my behaviour was dismissed as "shyness" and I was seen to be "loner" which allowed everyone to pretend that I'd simply "grow out of it".*

It may also be important to appreciate that the family members on the spectrum are unlikely to have the same amount of mental energy (reserves) as neurotypical members and therefore they can find it difficult (or impossible) to keep going in terms of activity and liveliness without having to withdraw to peace and quiet for a time to recharge. This does not necessarily mean they are in a mood or intending to be antisocial, merely that they may be feeling somewhat burnt out as a result of how hard their brain is having to work to keep up with everything that is going on.

It could be argued that mutual trust along with respect is the foundation for any relationship. This is especially true in intimate, personal relationships. For some people on the spectrum fear of ridicule is a barrier that can arise from repeated exposure to difficult social interactions or that may be anticipated based on restricted experiences. Also the often transient nature of contemporary relationships can make it difficult for people to gauge the nature of the relationship (i.e. the level of likely commitment of the other party). This can make people wary of being vulnerable.

They may be reluctant to address the issue with the other person for fear of seeming too intense or 'heavy'.

*I struggle to keep friends – I can make them if they have similar fields to my interests but I seem to be more intense and interested than them, so this puts them off. I struggle with my teenage son as I like rules and order and his obsession just now seems to be about chaos and mayhem.*

Some of the thinking and processing patterns of people on the spectrum makes it difficult to conceptualise, visualise and adjust perceptions i.e. imagine how the other party would feel about / take a specific action or gesture given the relevant context. There is therefore a tendency towards rigid patterns of thinking that can remain unaltered despite concrete and or logical evidence to the contrary. The person may have difficulty reading situation specific information and may therefore tend to apply generalised concepts. Fear of ridicule based on previous encounters or anticipated outcomes can get in the way of relationships at all levels, particularly at this intimate level. Males may be afraid of coming across as inappropriate or 'sleazy' as a result of misreading the signals.

Difficulty reading, interpreting and responding to the range of characteristics of individuals is a barrier to trust and this too can get in the way of relationships. It can appear that the AS party simply does not have regard for the other party's views or feelings. The AS person will likely need to be told what you feel, think in the situation and more importantly why you feel it. This (usually) unspoken information (inferred) is what often seems to form the ever increasing backbone of a relationship as this knowledge is acquired overtime and put into practice. So it is clear why a lack of this ability hinders intimacy or indeed relationship forming in general.

*Some time after I married my first wife and she told me she wanted to start a family, I found that I could not cope with the concept of becoming a father, and said 'no'.*

The reciprocal nature of trust is important. One individual describes the expectation of trust as an "insult to common sense. This is a powerful yet understandable assertion when the intentions and motivations of people on the spectrum are so commonly misunderstood or not recognised. Typically trust builds over time however some people with AS are not willing to take such a high level risk and this can add to their reluctance to enter into relationships for fear of being hurt.

Anecdotal evidence suggests that some individuals, notably fathers, come to a diagnosis of AS or come to consider themselves as having AS following the diagnosis of a child with an autism spectrum disorder. It therefore seems inevitable that professionals will encounter people who are on the autism spectrum and who are parents.

*I hate that people don't like the fact that I have children, I've been told that it shouldn't be allowed, I've been told I'm a bad mother. I want to be recognised as an autistic person who has an autistic (and typical) children. I am an autistic mother but there is no facility to support that: not when my kids have appointments, not at their school, nowhere.*

This is likely to be due to the fact that it has only been relatively recently that the intimate life of individuals on the spectrum has been given the same recognition, in terms of its importance, as in typical development. Hendrickx (2008) confirms that the notion that people with AS are not interested in relationships or marriage is well recognised as being inaccurate and outdated

*Due to the conditions explained I have never been in an adult relationship which is frustrating.*

Consequently relatively little is known in research terms about this aspect of daily living. To understand this vitally important area of relationships there is strong reliance on anecdotal accounts and on the increasing life writing of people on the spectrum. The limited research that is available is useful in supporting personal and professional understanding of the needs of those on the spectrum who become or desire to be parents.

Aston (2003), herself the partner of a man with AS, undertook research involving 41 adults with AS. All were in, or had previously had intimate relationships. 35 of their partners also participated in her study. Participants were a mix of formally and self diagnosed individuals. Six participants were female. Parenting experiences accounted for one area explored in the study. She asserts that AS is not necessarily an indicator of poor parenting just as those who are typically developing are not routinely good parents. She argues that a range of factors influence parenting capacity and style including an individual's own experiences and upbringing, general demeanour and personality as well as external pressures on the family such as financial issues. These issues are recognisable for the typically developing individual who becomes a parent however she does acknowledge the potential for increased stress and anxiety within the family where one or both parents have AS.

Professionals who are involved in supporting families need to be sensitive to the potential implications where there is a parent who has AS. In this context it is essential to set aside typical interpretations of behaviour. Such an approach requires professionals to be open to setting aside their usual frame of reference and to consider the implications of the dynamics and interactions of a family where one or both parents has AS.

### **Summary**

It is clear this is a complex and highly individual area of living. There are a number of implications and key messages for professionals who engage with and support people on the spectrum.

It is critically important to be mindful of misconceptions associated with this area of daily life. Assumptions and prejudices are among the biggest barriers to people in being able to understand, articulate and pursue their needs in terms of their own network of relationships.

The sustained and considerable effort people on the spectrum need to invest when engaging with other people at any level is worthy of admiration. Supporting Individuals to reflect on the types of relationships they need and want rather than imposing the stereotype of autism on individuals is an important starting point. The mutual responsibility that is inherent in all relationships should be emphasised and explored. People on the spectrum are often all too aware of their shortcomings

in relationships and interactions. This can blind typically developing “partners” to their own deficits in this area resulting in fractures in relationships being perceived as the AS person’s fault by default. It is therefore as important to explore interactions and events that go well as those that go badly.

### **Reflective questions**

- Have you made assumptions about people with AS in terms of their desire to have relationships?
- What could you do to help people with AS to build a positive sense of self identity?
- Have you thought about people with AS in a parenting role? Do you have any preconceived ideas that influence your thinking about this?



### Chapter 4 – Education and training

Academic skills, vocational skills, life skills, Careers, Schools, units, colleges, university.

*“My experience of school was fraught with anxiety. I have sought many times to articulate just how I felt and, as yet, have still to find the words to adequately encapsulate it. My recollection of the time is somewhat hazy – as can often be the case with AS and associated Specific Learning Difficulties (SpLDs), or so I’m told. Perhaps this is counter-intuitive to what one might expect given just how traumatic I purport to have found the whole experience. I do know that without relent I felt sick to the stomach, perspired profusely and my body seemed to be on a constant state of red alert - my muscles taut with tension. Everything and everyone seemed to move at such a rate and with a fluidity and spontaneity I could never engage with - interacting with each other, with the teacher and with the environment at large. I felt they were water, I was oil – slow and thick and unable to mix. Even at aged four I remember begging my mum not to send me to nursery school and she recalls me pleading earnestly with her to ‘drive slowly, mummy’ as we approached.”*

#### **Introduction:**

For many people with Asperger’s Syndrome their school days have been a long way from being the happiest days of their lives – often emotionally painful and mentally exhausting to say the least. For some individuals the school experience is what affirms their insight into “being different” (for examples see Sainsbury 2000) and woefully accentuates their inability to fit in, even when there is an earnest desire to do so.

Ironically many individuals with AS are very academically able but the social demands of school give rise to crippling levels of anxiety that can have a serious impact on disposition and motivation to learn as well as physiological ramifications in terms of elevated stress levels impacting on learning ability. There may be experiences of bullying (Dunlop et al 2009) that can have lasting repercussions on confidence, motivation and self esteem. There may be a lack of adaptation of approaches to teaching and learning and to the learning environment itself. It could be suggested that this is owed for the most part to the obvious need to cater for the majority, but also to the failure and/or inability to adequately assess, understand and innovatively cater for a population with such a diverse and complex range of needs. Ultimately, this results in very real and significant barriers for the learner who has AS.

It can therefore be seen that in such circumstances academic ability alone is of limited value in educational settings where the vehicle to learning is often interaction with others. It may even be argued that academic potential can be choked or extinguished by the inappropriate learning environment.

In contemporary society there is a drive to encourage lifelong learning. In many ways people with AS are well suited to this as a philosophy however they face many real challenges and barriers to realising their aspirations – particularly when there is likely to be a cumulative effect from rejection and (perceived) failure. In this section we will consider education and training in very broad terms. We will consider aspects such as vocational and life skills alongside more formal education.

### **Personal & Professional Perspectives:**

Training of professionals involved in the education of people on the autism spectrum is important yet inconsistent (Mackay and Dunlop 2004). There has, rightly, been a drive for education to be both inclusive and accessible. The skill and expertise of the teacher, college or university lecturer needs to be augmented with the appropriate understanding of AS and the spectrum in order that they are prepared to and able to make adjustments to their practice.

It is important that training for professionals should highlight the potential strengths, skills and abilities of people with AS in addition to highlighting the challenges that people with AS may be likely to face.

The main focus of this chapter is education however people with AS are likely to be exposed to a wide range of professionals throughout their lives. Whilst it is unrealistic to expect that all will have high level expertise in AS there is a need to be “autism ready”, that is to say that they have enough knowledge of the autism spectrum to make their specific professional skills useful to the recipients of their skills and services.

People with AS may themselves need and want to access education and training opportunities to support their self understanding. This needs a careful and well considered approach that starts with access to good information that promotes optimism rather than despair. It can be challenging to find a common language that is appropriate and that reflects the views of all individuals. None the less the focus in professional interactions with people with AS should be on capacity and competence rather than deficit and impairment.

As previously mentioned the academic ability of pupils and students is not usually a barrier. Understanding social expectations, negotiating a wide range of social situations and navigating the physical environment can be challenging to the extent that they present very real and often poorly understood barriers to learning.

Noticing and paying attention to social behaviour is an important step in understanding the range of contexts that can be fraught with anxiety for pupils and students with AS.

*“I felt conspicuous and highly awkward and as a result, I often withdrew or stayed on the sidelines feeling markedly inadequate but having absolutely no idea how to ‘get a grip’. I sat at my desk practically mute – my palms dripping with sweat, often smudging and creasing the page. I did not want to draw attention to myself – I had a fear of being ridiculed and felt vulnerable and exposed. I stood (or sat) around on the periphery willing the day to pass quickly - never feeling able to just relax and go with the flow. I kept my mouth shut and thankfully was able to stay beneath the radar it would seem in terms of being bullied, or indeed the teachers realising I had a problem. Perhaps if I had been ‘savvy’ enough I would have avoided school when I was old enough, but then where would I have gone?”*

The above represents an all too common reflection on school. In this context it is difficult to understand how such obvious signs of stress and anxiety can be missed, yet they are and the consequences can be pervasive and damaging to individual well being.



Peer relationships are a vitally important part of school life. Many people make friendships in their school years that remain with them well into adult life.

*When I think back on it I always let others come to me. I did not feel equipped or worthy. I seemed also to have an inherent fear of being rejected and hurt and as a result 'guarded' myself by not putting myself out there so-to-speak. Occasionally people would come to me but I always felt the connections were very tenuous. I think before long they probably either became bored with me and/or disillusioned by the lack of reciprocation on my part.*

Professionals who engage with pupils and students with AS in formal and informal educational settings need an understanding of how everyday issues can be anxiety provoking and problematic. The following offers some insight into aspects of [how](#) ordinary day to day issues can pose real challenges for people. The response to and level of understanding of the significance of these issues can make the difference between a positive, affirming experience and one that is negative and damaging.

Often it can look to the teacher that an individual is coping although internally they are in turmoil. This is akin to a duck seen swimming on the surface of the water - seemingly smooth movement, but underneath the feet are going like the clappers. It is important to bare in mind that not only do individuals on the spectrum have a problem when it comes to their brains decoding body language, tone of voice etc but communicating or 'emitting' thoughts and feelings verbally or non verbally is also an issue. Individuals can look one way outwardly whilst the reality of the situation is very different indeed.

Given the degree of sensory stimulation in the school environment, coupled with the inter-relational issues experienced, having a supervised room in schools where pupils can go if they want peace and quiet could be a lifesaver. If an individual has trouble tolerating the hustle and bustle of the playground/corridors in addition to the social aspect it is a chance to recover/recharge/escape where they can be quiet, read or study.

Whilst many people with AS have the intelligence and ability to learn and acquire life skills, the manner in which they are taught can often be inaccessible.

There maybe something to be said for teaching 'practical' life skills such as cooking to people with AS in a more scientific manner i.e. making less room for inference and 'commonsense' and more room for logic - particularly explaining *why*. For example, stating *why* a product should be cooked for a certain time e.g. 'if this meat is not cooked for X minutes it will be unsafe to eat' rather just saying 'cook for X minutes' which leaves ambiguity as to the importance of it being cooked for X minutes. Is it for optimal taste (cooking for 10mins less would be fine health wise if in a rush but not ideal for maximising palatability)? Also stating why certain procedures are done rather than just assuming one can infer e.g. this is added for aesthetic purposes, this is done to add flavour, this is done for emulsification or for preservation.

The message here is that it is important to ensure people with AS are taught life skills and indeed academic subjects in a 'language' they can understand and not made to feel inadequate or 'stupid' because they do not understand in a conventional manner.

Such approaches require no more than concentrated thought, willingness and a little extra effort but they can make a vast difference for people with AS.

Subjects and activities that may ordinarily be viewed as enjoyable and fun will not necessarily be experienced in this way by the person with AS. School trips and outings, assemblies, P.E and un-timetabled parts of the day can all potentially signal stress and anxiety for the person with AS. Again this need not be the case – as with planning, forward thinking, and staff with the right skills there is no reason why such situations cannot be accessible and enjoyable.

Some individuals with AS have a strong drive for thoroughness and perfectionism. This may manifest in over working projects, rubbing out whole pages of work even if they only contain a minor error or there may be strong emotional, seemingly disproportionate reactions to failure or challenge. From some angles such pedantry can be a strength - but it can also be a burden. Developing strategies to support coping with and managing these tendencies is important.

Many people with AS are academically able. Such skills are often juxtaposed with difficulties in planning, predicting and thinking in flexible ways. It is of course important to capitalise on intellect but not at the risk of other aspects of learning and development. One individual said of his school years, “I don’t know what they were preparing us for but it wasn’t real life”. Knowledge acquisition is important but so too is knowledge application. Good rote memory is often an asset however using knowledge in context, particularly social knowledge can be real a challenge.

### **Summary**

Educational opportunities are vitally important for people with AS. Professionals working in such settings can have insufficient training and insight to adjust practice to meet the needs of individuals. Training and knowledge is important, but so too is a willingness to accept the person as they are. It may be difficult to understand why a very academically able person seems to struggle with what might be termed common sense decisions or actions.

Social interaction difficulties may be apparent but may be too readily assigned to typical frames of reference such as shyness or adolescent behaviours. In the absence of mandatory training in autism for every professional in education and other sectors it becomes incumbent on individual professionals to be open to learning from the individuals they encounter and to be guided and informed by them.

### **Reflective questions**

- Think about the range of learning environments that you are familiar with or have experienced. How might these be perceived by people with AS?
- How willing are you to make adjustments to your established professional practice to accommodate the needs of learners with AS?
- What have been your perceptions about people with AS and their potential to achieve in an academic environment?
- Do you value diversity and difference or are does it make you feel challenged and uncomfortable?

### Chapter 5 - Transitions into adult life

Approaches, preparation, family support.

Much has been written about transitions out of school, into work, through life stages and into growing older – a topic addressed later in another chapter. Here we offer points from our discussion specifically on transitions into adult life. For most of the group there were more significant current transitions and these form a thread through each of the other chapters.

Transitions are a dynamic time of change with accelerated developmental demands.

Autism is a developmental delay - this means it takes us longer, emotionally speaking, to be ready for the next step in life. For many people on the spectrum, as with me, when they think about the major transitions in life - starting primary school, starting secondary school, starting university, leaving home, getting a graduate job, becoming qualified in that job - they say they weren't ready for any of these major steps when they happened. This is definitely one area in which realisation and recognition of being on the autism spectrum has been advantageous in terms of providing an explanation for difference and difficulty.

*Primary school was fine enough as different behaviours is deemed inoffensive around other young children. Secondary school however was a difficult time as transitions into future adulthood and pressures of knowing what career path you are expected to take had taken its toll. The transitions from primary to secondary school was a nightmare for me. All I wanted to do is play but circumstances and puberty started to dictate moods. Bullying was rife and teachers appeared to struggle on how to deal with my "different" behaviour. I was looked upon as a troublemaker rather than someone in need of help. It eventually had taken its toll and a point of crisis (and suicidal thoughts) came to fruition. It was then my (voluntary) hospital stay began.*

*Personally speaking, in the past, I have found transitioning very difficult, stress-inducing and I'd even go as far as to say often traumatic.*

*Very stressful being a carer to my Dad and having someone be so dependent on you along with coping with autism and depression.*

*From very early childhood I would find any change considerably disturbing – in my assessment this seemed markedly disproportionate to what the other children seemed to experience. I'd often feel physically ill – dizzy and sick, with a pain in my stomach. I guess looking at it retrospectively I recognise it as a state of high anxiety – akin to a fight or flight response that in the event neither fought nor flew.*

*I would beg my mum not to send me to nursery school because I couldn't bear it – I was so overwhelmed and that was to be a token of things to come right throughout school. It's very hard to articulate the emotions no matter how hard I try – an overarching feeling of being ill-equipped to cope – fragile and exposed. I hated going to other children's houses – if I did I often couldn't function and ended up complaining of feeling ill to get home again. I recognise now that I lacked the intuition*

*to know how to 'be' – fluidly perceive the expectations and behave accordingly. The suggestion of staying overnight at someone else's home was insurmountable and I did not feel able to begin partaking in sleepovers etc until I was considerably more advanced in years than my peers – even then I found it to be far from enjoyable.*

Not being ready means not having the skills and emotional resilience for the next step. Not having enough skills makes failure more likely. Repeat this is few times and you get fear of transitions.....fear of change. A lot of the stress and anxiety associated with transitioning stems from difficulties envisaging or imagining what a situation or environment will entail and pre-empting and anticipating corresponding expectations and conduct.

*One can therefore find oneself feeling like a deer in the headlights generating enough nervous energy to power the national grid. Superimposed on to this is the significantly reduced ability to think flexibly /on ones feet in response to the environment and its stimuli once one is in the situation. In essence this makes new situations and stages very bewildering until you learn, predominantly through repetitive experience what an environment involves (as opposed to instinctively reading it in 'real' time).*

Its not that we cannot change and develop - we can change and develop. If we could make changes when we are actually ready rather than when we reach the age when OTHER people are ready, we could build our confidence and skill. Perhaps in order to minimise the stress of a situation or new environment it may be an idea to gather as much information and knowledge regarding it beforehand as possible. By this I mean reducing the extent to which it will feel alien. Visit the building or premises if applicable to familiarise yourself with it beforehand and meeting the relevant individuals the situation may involved. Even photos of individuals may be of value - lessen the often overwhelming effect of meeting many new faces simultaneously or in quick succession. For example, if starting college look around the building – the lecture rooms, canteen etc and look at the lecturers' online profile to see what they will look like.

If it is a life stage that is the transition in question it may be helpful for the people supporting the individual on the spectrum to give more information than would be deemed necessary for an individual not on the spectrum – essentially to compensate for the lack of ability to infer or imagine what it will be like. Going on a trip away they might need to be told what might be needed as the ability to imagine situations and run them through in your head, never mind anticipate eventualities, is likely to be significantly reduced. People around a person with autism need to develop their own forward thinking in order to help that person prepare for change.

### **Reflective questions**

- As a professional how aware are you of the day-to-day transitions that may occur for individuals with AS in your service?
- How do you currently prepare for these transitions?
- If you are aware that someone with AS is anxious about change, how do you respond?

### Chapter 6 - Autism and Employment/Employability – The Occupation Spectrum

**Employability:** Full time employment, part time employment, self employment, apprenticeships, internships, social enterprise firms, engaging employers, strategies in the work place, volunteering as a work preparation tool.

*I have never had a day's unemployment in my life and have stuck with the same employer for nearly 30 years - I have no idea about how I would get another and no transferable skills. I have always found work situations difficult to deal with, but despite that I have moved jobs a few times and even been promoted. I rarely have any sick leave (I've not taken a day off sick for 13 years), always do jobs to the best of my ability and will go out of my way to help colleagues. However, I still feel that my abilities are under used and that I am continually taken advantage of. I therefore live with constant feelings of not being valued and my abilities not being appreciated even when I know I have done considerably more than is required of me. To add insult to injury, colleagues with far less ability, but who are "networked" and can talk "corporate speak" are constantly promoted over me compounding my feelings of worthlessness.*

#### Introduction

There are already several books and guidelines that describe the typical strengths of the person with autism in the workplace, the typical difficulties they face and the strategies that can be used to overcome these. It is not the purpose of this chapter to repeat these, rather to give an insight into the reality of the employment experience of people with autism and to consider the importance of work and the untapped potential of people with autism.

When we discuss employment, we need to be conscious of the terminology we are using. Word such as “work”, “employment” and “occupation” all have their own limitations and can restrict the reader’s thinking to one form of occupational outcome. For the purpose of this chapter we will use the term “employment” and this includes consideration of occupational outcomes that are not paid, open employment in the traditional sense. We are essentially describing how the person spends their time and what they do.

Leading a purposeful and occupationally full lifestyle is important for everyone. Employment is as important to the person with autism as anyone else. Just as with every adult, people with autism will seek to identify themselves by what they do, either in employment, other occupational activity or volunteering. It may be that this is even more important for the adult with autism who may be less interested in the social aspects of their lives. Many autobiographical writers with autism talk about the importance of their work. A National Autistic Society survey of adults with autism identified that when asked what would most improve their lives the top priority was employment (Barnard, Prior and Potter, 2000).

It is also an expectation of society that where someone is able to enter paid full time employment they should do so. However, we know that success for people with autism can often depend on doing the right thing at the right time. It may be that the individual with autism will take longer to become ‘ready for work’.

For some, the pressure to enter employment as soon as they may appear to be ready, is not helpful, counterproductive and in the long term a more staged approach is better.

*Was offered a job while in college to start a number of months after finished my course but I kept getting put off and it fell through. Was badgered by Job Centre straight from college, they wanted me to go into a Call Centre which would have been a nightmare.*

When a young adult leaves school or further education, the priority for their first employment experience is likely to be to get a job, enter the world of work, learning skills and workplace behaviours and then in time aspire to the to work towards the type of job or career they prefer. However for the person with autism it may be that they need to develop these workplace skills outside of a work setting and move into the “ideal” job at a later date.

*When I left college back in June 2000, I was a bit lost in term of where to go with my future. Through support from mental health social development I was introduced into the local Mental Health Forum. From then I was in a committee environment and in a period of 10 years (through different organisations) I have worked voluntarily as a committee chairman, secretary and treasurer alongside newsletter editing and background work with different mental health groups in the community. At the end of all this I've finally worked out my career path - an administration/office worker.*

There are obvious financial benefits to paid employment and the independence that this brings. However it is the experience of many individuals who are in receipt of benefits is that to enter paid employment can result in a net loss of income. This traditional view of the ‘benefits trap’ is disputed by some who argue that with the right knowledge and motivation there are ways to work this system. However, the experience of people with autism is that this is a real challenge and can prohibit a gradual introduction to paid employment. This is a complex area and knowledgeable support from benefits advice services is required as the benefit package that the individual may be entitled to is specific to the individual. It is also important that these services are tuned into the unique needs of the person with autism.

In times of economic difficulties, there is an even greater need for all individuals who can be self sustaining economically to be financially independent. This need is increased by the expectation of society that people who can work, should do so.

A recent survey by the National Autistic Society found that only 15% of adults with autism in the UK are in full-time paid employment. Furthermore 51% had spent time with neither a job, nor access to benefits and 10% of those having been in this position for a decade or more. The desire to work however is high, 61% of those out of work say they want to work and 79% of those on Incapacity Benefit say they want to work (2009). Whilst full time paid occupation is not necessarily the right solution for everyone, this figure clearly shows that people with autism are being significantly undervalued in society and not achieving their full potential.

### **Professional and personal perspectives**

We know that the talents and strengths of people with autism can lead the individual towards employment options that are compatible with these strengths. Typically we

know the attention to detail, likeness of order and sticking to the rules can be of significant benefit in occupations that involve mechanical, scientific, and organising tasks.

However, as with everything else, the person with autism is a unique individual and a one size fits all approach is never going to be helpful. Whilst what we know about autism can be helpful in suggesting career paths that will match talents and interests; equally there are successful people who do not follow the typical path into employment and there are people with autism who are successful in professions which involve creativity or social empathy.

*Stressful situations can lead to acute anxiety/depression – and many neuro typicals don't realise this. Eleven years ago, I was off sick from work for 2 months with a depressive illness, triggered by a work situation which got out of control at the time.*

It is useful to consider what the typical employment experience is and look at a few of the obvious areas where difficulties can occur for the person with autism but that also could easily be avoided or altered to make the work experience better for the person with autism: panel etc are likely to be helpful for all candidate including those with autism

- Working environment - simple adjustments can make a huge difference, particularly for those with significant sensory sensitivities which are reported in individuals throughout the autism spectrum. For example the change in workplace environments towards open plan offices may make business sense in many situations but for those with particular sensory sensitivities it can be a difficult environment in which to concentrate.
- Interviews – are often very socially orientated experiences with a lot of non verbal communication taking place. Information about the process, interview location

*I always had difficulties with job interviews, as I don't know how to answer hypothetical questions. My present job I did not get through an interview, but by showing (first on a temporary basis) how I work. There ought to be more opportunities like that for people with ASD.*

- Job descriptions - seem to be increasingly describing the same job. In every job you need to be a “team player” as well as someone who can “work under their own initiative”. Then there is the catch-all phrase at the end “and anything else you are asked to do”. This is not helpful for anyone who is looking for the job description to actually describe what the experience would be like on a day to day basis.
- Job promotion – career progression often equates to moving into management of other workers.

It is worth considering the concept of a spectrum of employment or occupational outcomes that are possible for everyone and what these might offer for the person with autism. The options include:

- **Self employment.** It is recognised that self employment for some people with autism would be a beneficial option yet it would not normally be considered (“Go for it!” Ridley, Hunter and Infusion Cooperative, 2005) (iwork4me, 2011)
- **Open employment:** (Sometimes with support to enter the workplace). There are support services the support the person to develop workplace skills and to enter open employment (NAS Prospects scheme and Intowork in Edinburgh are examples)
- **Sheltered or supported employment:** Real paid employment in a setting where there is ongoing access to support
- **Created employment:** It can be more successful when employment opportunities can be created around the skills, interests and talents of an individual or group of people with autism, rather than trying to fit them into existing work settings. Social Firms and Social Enterprises are example where
- **Occupational activity**
  - a. Volunteering: This can be an important part of the development of an individual's confidence and work skills.
  - b. Life skills: For some individuals their ability to engage in overtly employment related activity seems to be a remote possibility and their daily programme of activity would be best described as life skill support. However, such individuals will nearly always have skills and interested which can be encouraged and used to develop a lifestyle with meaningful daytime activity and occupation. The activity may appear at face value to be leisure or recreational based about that same activity can be structures to have real learning opportunities that link to the development the persons employability skills. For example visiting a café, the person can be learning about new environments, turn taking, acknowledging the needs of others, listening skills etc. all of which may be requirements for the person ...

This list is not exhaustive and there are as many unique occupational outcomes as there are people. At all levels of the spectrum there are individuals who are not being engaged and where there is wasted potential and opportunities are being missed.

*Hardly enjoyed my experience of university one bit, apart from having the degree, due to extensive problems with finances and especially interpersonal relationships. Studying was very different from what it was in high school, as in comparison it's what you make of it, and I wasn't well prepared for that.*

The occupational spectrum concept also tries to show that all the different options have equal value.

In an ideal situation the individual would have access to all these different options and would able to access the right alternative at the right time in their lives. Nor should the spectrum should not be seen as one where everyone would necessarily progress from one option to the next. If we start from the viewpoint that all people with autism have the skills and desires to make a contribution, then we can aim for positive outcomes such as having more money, increased self-esteem and self-confidence, and having friends at work.



### Summary

It is useful to reflect on the great achievements that have been made by people with autism (Fitzgerald, 2004; Fitzgerald and O'Brien, 2007). Clearly not everyone with autism is a Michelangelo, Newton or an Einstein. However, the world had benefited from the achievements of people with autism and will continue to do so.

Temple Grandin (an author with autism) describes the benefits that people with autism have brought to the development of our society:

"... social people did not invent the first stone spear. It was probably invented by an Aspie who chipped away at rocks while the other people socialized around the campfire. Without autism traits we might still be living in caves."

Grandin 1996, p.8

### Reflective questions

*For the person without autism:*

- Consider autism and employment in the context of your own work experiences
- What are the reasonable adjustments that could be made to your work environment that would make it more accessible for a person with autism

*For the person with autism:*

- What are your employment ambitions and aspirations

*For the employer:*

- What simple adjustments could be made to a job to make it more accessible for the person with autism
- Should a person with autism declare this to their colleagues? What impact do you think this would have?
- What are reasonable adjustments?



### Chapter 7 - Leisure and Wellbeing:

Leisure and wellbeing: Music, art, crafts, drama, sport, a quiet time on the internet, the open countryside can all afford enjoyment and relaxation.

One of the most important things in life that applies to many people with Aspergers, is to have a regular amount of time each day for carrying out leisure activities. It is by doing whatever we enjoy and what makes us feel relaxed, that can make the difference between being able to cope with our day to day lives and not being able to cope at all. We might not describe these activities as leisure –

*I've been retired from employment for 16 years now, and all the activities I pursue, like e-mailing and keeping my computer in order, and looking after my 5 satellite TV dishes, and weeding in the garden, sweeping the paths outside, trying to keep things neat and tidy inside, etc. etc. I regard as necessary "work" for survival and for making my life comfortable, rather than as real leisure. For me, everything has to have a purpose, and so I tend to think of "leisure" by its definition, as a waste of time.*

I'm sure this is more important than ever to those on the spectrum, trying to hold down a job. Having time to spend on whatever we enjoy, be it walks in a park or organising a collection of postcards etc. for a regular amount of time every day can help to control the stress of managing to get through the working day.

*I need to spend quite a lot of time on my leisure activities in order to cope with my day to day life.*

People who don't have AS will often relax after a day at work by chatting to a partner or friends in the pub. Being able to talk to others about work etc is important for Aspies too, but probably much more important is to be able to get a break from communicating with others and this can often be having a chance to indulge in our favourite leisure pastimes.

*I have always been obsessed with collecting and since adolescence I have been particularly obsessed by music and collecting records, CDs and books on the subject. I also learned to play guitar, but discovered that I am not naturally gifted, so advancing has always been very hard work. I am specifically interested in jazz and all forms of early recorded music, but have always also been very interested in contemporary music and was a punk in the late 1970's. This interest has been the only thing in my life that has constantly given me pleasure, but my obsessive collecting has meant that I can hardly move in my home due to the quantity of materials I have collected. While this causes me problems, I could not imagine giving the collection up as each item means something to me.*

Some Aspies join specialist groups to meet others who share their hobby and this can be a really good thing. Other people with a strong interest in a similar thing are often much easier to chat to and there is not the pressure to be up on the latest TV shows, films etc if you don't want to be. There are also some hobby and leisure clubs which may be more likely to attract people who are on the spectrum or not far off it, so meeting others who are easier to get on with can be a positive thing.

Leisure activities can also be solitary and those which involve quite a lot of concentration can be really good for taking a person's mind of worries and giving the brain a rest from analysing problems over and over again. Often just having a break from thinking about a worry can make it seem much more in perspective.

*I attend a theatre to watch various things and the staff recognise me - the openness/light of the place is good also I like going for a coffee at a major coffee place and again the staff know me by name and are especially polite to me and help me or tip the extra treat or joke in - it feels safe quiet and the choice in music makes me laugh because it can be very odd*

One of the challenges for someone with AS is managing to fit enough leisure time into their day. Often there are so many demands on us that it can be near to impossible. An important thing is to have good assertiveness skills which can be used when people try to get us to do this that and everything for them. I imagine this might be more of a problem for those who aren't working as they can be seen as available. It can be very difficult to even notice when this is happening and before we know it we are stressed and depressed and can't figure out why. The reason is probably most likely that we have not been spending enough time on things that make us feel relaxed, ie our leisure interests, and just being able to potter around and do what we feel like for a while.

Everyone needs time to themselves but it is more important to those with AS than ever as without a reasonable amount of this we will fail to function very quickly.

*Do enjoy walking in hills as it's very quiet there and no-one else.*

*Enjoy going to the country, where the vast space is wonderful.*

Often people with Aspergers can suffer from depression and severe anxiety and frustration too at not making friends or whatever.

*Choosing activities which interest me, mainly those which I can do alone or in small groups, a chance to have time out from the areas of stress in the world.*

We might then feel like our leisure interests are a waste of time and not getting us anywhere. It can be a good idea when this happens to write down a list of any things we might get enjoyment out of even if only a little bit of enjoyment and try to fit more of those into our day. Maybe a new interest could be taken up where instead of just going for a walk in the park, the walk could include learning how to identify trees or wild flowers.

*I would really like to engage in some activities where I could contribute something of benefit to others, instead of my rather pointless solitary existence at the moment. If I did that, though, it's arguable whether it would actually qualify as leisure.*

Many people with AS get a lot of enjoyment out of music, either singing or playing a musical instrument. Music can be very therapeutic. Others can get a lot of enjoyment from caring for either plants or animals or creating art or cookery.

*My hobbies, like playing in an orchestra, singing in a choir or doing art and craft are a very enjoyable link with other like-minded people and a way of relating that bypasses social chit-chat.*

Often people on the spectrum feel embarrassed about their favourite hobby(s) as they are different to what NT's would normally do with their spare time. The reason for this will often be that we are mocked about our hobbies because they are not what everyone else likes to do. I think this is probably more the case with younger people on the spectrum ie teenager and young adults. It maybe isn't seen as cool to be into collecting stamps, studying everything there is to be known about Horses. For some reason you are expected to be out clubbing and going to pubs and admitting to spending time on a favourite hobby can bring about teasing from peers. I think it is important to try and not let this bother you as once people get a bit older many of those same people who were belittling the Aspie about their hobbies, will be looking for some leisure activity to pass *their* spare time. People who have interests are more interesting than those who don't anyway and often get to meet other people interested in the same thing.

Even if you don't keep up the favourite pastime it will be something to look back on and remember in later life.

*The barriers to accessing leisure activities for me will always be financial. If you are on a relatively low wage you have to be careful how you spend your money as every penny counts. if you enjoy activities like collecting then you can end up in the situation of having to make choices between going on holiday or being able to pursue your hobby. While it is of course true that most people will not be able to do everything they want, being able to pursue hobbies for people with Asperger's is particularly important as many have little else in their lives, and it is often these hobbies which give their lives any kind of meaning or purpose.*

For many it is important to feel you are with like minded others

*Most of this is through Number 6 where I'm doing things I enjoy with people I enjoy being with.*

*I like being with people in my leisure time. I love it when I have a meal at someone's house. I cultivate friends with trampolines.*

Time off, whether in company or alone, is essential for many of us. Finding the right kinds of groups and the opportunity of taking part, meeting people and making friends should be an ordinary part of our lives.

### Reflective Questions

- To what extent do you think local leisure services and opportunities in your area are welcoming to a wide range of users?
- How do you judge when to be welcoming and take trouble to know people by name and when people may be glad of being left alone?
- Access to activities – to what extent do you take account of sensory issues?



### Chapter 8 - Community Access and Inclusion:

Community, inclusion, exclusion, awareness of community groups, supports, leisure opportunities.

*In terms of inclusion I think society needs to move closer to us than us to them.*

*They do not understand how much stress it causes us when moving beyond our comfort zone. To average folks stepping beyond the comfort zone is a challenge to be overcome: to me it is like trying to do a marathon whilst choked with the flu.*

Sharing thoughts about community inclusion takes us to the nub of daily living as we consider the extent to which people on the autism spectrum are, want to be or are not part of their local communities. Group discussion focused on whether there are barriers or difficulties for people on the autism spectrum in accessing the local community.

*In some places there are barriers and difficulties for people on the autism spectrum in accessing the local community. I live in a small village who have been very good to me – in larger places it is probably true.*

*I don't feel part of my community even although I've lived there for 23 years, I feel like an outsider. The solution to loneliness and mental health difficulties is not being taught how to think more positively about your bad situation. The solution is community. I find church an excellent source of community.*

The consensus is that simple things like going to shops or the supermarket, using public transport, paying bills all have their barriers. A number of the contributors feel that these experiences take years to find coping mechanisms in order to be able to deal with what is looked at as "normal everyday life". Accessing anything in the local community will involve speaking to people, if social skills are limited then this is always going to raise difficulties and the fear of being rejected because of any lack of social skills is enormous. It is therefore often easier for many of us to avoid putting ourselves in situations where you run the risk of rejection.

*Because they are shy about engaging with other people, they lack self-confidence, and they are busy with their daily self-imposed survival and living routines which are driven by their need to always aim for perfection. Rightly or wrongly, they don't feel they have anything much in common with the community and wouldn't have any idea how they could usefully contribute anything within the community.*

Barriers to local participation included some really practical issues, for example:

*For me, the barriers are mainly in the form of sensory issues, especially noise and lack of space. For example, I had a place in a weekly physiotherapy group at the hospital, but they insisted on having the radio blaring the whole time in the background and refused to turn it off for me.*

*Lack of understanding. A lot of places only have phone contact and I hate using phones.*

*The likelihood of being seen as 'different' - perhaps even persecuted - among people in the community who literally could be anyone. This would be true whether someone has grown up in the local community, going through school etc. in it, or whether they've come into it from outside.*

*The environment type, clarity of access, people's manners, perception of self or of place or process there*

Whilst such barriers are acknowledged, finding answers to social inclusion is more difficult. The experience of the Asperger Forum members suggests that part of the answer lies in being included and integrated with one's own community. The Forum seems to serve a wish to be with like-minded others with whom one can share experiences. Such groups mean that people feel part of a community – their own community - here people can feel part of a group:

*One of the group, not feeling odd or thinking you are.*

Smaller groups are favoured. It is important to suss out the right group and to ensure that it is an Aspie community that works properly, in which everyone can communicate and which people can write as well as talk and everyone makes an effort. Such groups **can** link to leisure opportunities. Communities change and its really important that all feel valued : there is nothing worse than '*Egocentric futility*' or *feeling worthless*.

Part of the development process for 'An Ordinary Life' included a number of opportunities to write statements about daily life and expectations. These few brief comments give some insight into the challenges of community inclusion:

*There are other languages*

*Diversity is ok*

*If diagnosis had been early and there had been autism awareness, this difficulty could be lessened.*

*Breaking down barriers is not really my thing.*

*People hate us.*

It was thought that a number of approaches could help, including:

- More awareness training should be provided for anyone dealing with the general public. This includes shopkeepers.
- The attitudes of society need to change and the fear that people in mainstream society have of those that fall outside of the mainstream needs to



be addressed. It is not wrong to be different and mainstream society should embrace difference rather than shun it.

- Better awareness of autism among the general public, though I don't know how this would be achieved. More sympathetic reporting in the press would be a start.
- Better information and training. More options for contact, like email.
- People need to adopt a customer focus, this has been lost over the years, a phrase its nice to be nice works for everyone and even breaks down people who are drunk, environments need to be more autism aware and this would help other groups, neuro-typical people do seem to like autism style environments too.
- Community workers should visit and interview us to determine our skills, our needs and interests, and give us a better picture of what might be available, and how we could usefully contribute.
- Greater awareness of what ASC is and it's affects.
- Liaison to help.
- Autism societies need to stop portraying us as in need of care: as people who can't speak up and don't deserve a voice. We need to be seen to be being accepted at all levels.
- People with AS need to be represented on the ASD Reference group: a person that would be elected by their peers to represent them. There is a self-run, self-funded autistic adults rights group in Scotland: they are not represented. We need to be included at all levels.
- Take into account people's sensory sensitivities and literal understanding of what is said.
- Create more opportunities for people with AS and NT people to work together : we'd all achieve more.

### Reflective questions

- How might inclusion in local communities be achieved more widely?
- Are there ways in which support with relevant social skills to enhance daily living and access to local services could be improved?
- What sorts of training is needed, eg awareness raising?
- How can self-representation be facilitated?



### Chapter 9 – Housing and Accommodation

Supported accommodation, residential, own tenancy, social housing, medical points.

**Cameo 1** - *Trevor lives in a tenement block in Edinburgh. Having shared flats for a number of years, he has learnt that he is much happier renting a flat on his own, although he finds that problems caused by his neighbours can make him feel quite depressed from time to time. His neighbour downstairs is learning to play the cornet and plays the same scale repeatedly. His upstairs neighbours put the washing machine on at night, and it has been known to be on at 2am and 4.30am. They know that his bedroom is right below the washing machine, as he has banged on the ceiling when it has been on. Sometimes, after he bangs, it will be turned off, but then put back on again. The situation 'depresses' him and throughout the day he worries about 'what it will be like that night'. Trevor can easily see how mental health problems occur as a result of neighbour issues.*

**Cameo 2** - *Leila is on her seventh flat share in 6 years: 2 of these moves have been a result of landlords selling their properties, but the rest have been the result of a breakdown of flat shares. Leila's name is on the list for a housing association flat, but she has been told that she is low priority and her diagnosis of Asperger's Syndrome does not recognise any medical points from the council, as she is not physically affected. Leila is 26 and much preferred living with her family, as they at least understood her need for space and privacy, but, unfortunately, this could not be sustained. For the most part, Leila has shared with more than one person. She has found this really difficult, as she is young and there is pressure on her from other flatmates to socialise and spend time in the communal areas. Leila likes to spend time with other people, but on her terms and only for short periods of time. Sometimes in the flats she has shared, Leila has been seen as the odd one out. She has felt so victimised and pressured by other flatmates, and made so uncomfortable, that she has terminated her lease. She is constantly looking for other flats, to the point that all her time is consumed either by looking for other places to live, or by waiting for the current flat share to go wrong. She cannot afford to live on her own, but neither can she afford the damage to her confidence and self-esteem, caused by sharing.*

#### Introduction

There are many issues related to housing and accommodation, often issues are very personal and particularly sensitive for people with Asperger's Syndrome. Hypersensitivity to noise and smells can make flat and tenement sharing highly problematic and is certainly an issue overlooked by local authorities when grading priority for housing. With experience many people on the spectrum find it preferable to live alone though it is generally viewed as normal for the young to share flats.

*I only managed to break away successfully from the family home in my early twenties because I got a place in a college in another city – and I also a job there with help from a friend. My initial housing situation for was shared bedsits. I spent most of my time working at college or my evening and weekend job. There was a quick turnaround of roommates and I also changed premises often. I lived in about a dozen bedsits in about 16 months. My roommates were a vulnerable group of*

*characters whom I felt some vague identification with but we never got close which suited me fine.*

*Halls of Residence tend to be an option for only the first year, with students normally getting together to share flats in subsequent years. I found the social environment at university overwhelming, with it being very difficult to fit in and make friends. I certainly did not know anyone well enough to share a flat with them. For the start of my second year I found myself moving into a flat where there was a vacancy to make up four flatmates, flatmates whom I did not know, indeed this was the way of things until I left university. In this new flat the other flatmates did not take to me very well, so much so that I was forced out of the flat after just one semester.*

*I made some contacts through college and shared rented flats with them. Eventually, I ended up sharing flats with a group of ex-students who were stranded in the city because they didn't want to return to their own hometowns. For a several years this was a good housing solution for me but most inevitably moved on.*

In identifying the kinds of things that are important, it must be remembered that individual experiences differ and are often personal to an individual. Some organisations and local authorities, in trying to support housing provision for people on the autism spectrum have not distinguished between the varying points on the spectrum and, therefore, the vastly differing areas of need. Here we identify some of the areas that can be challenging –

- Establishing your own space in a space shared with others (to avoid sensitivities being aggravated by proximity to people who could be noisy)
- Privacy
- Prefer to live with family as understood
- Sensitivity issues
- Good to be living somewhere you feel safe
- Being the victims of antisocial behaviour
- Attitude (e.g. of police ) towards an area
- Can buy bricks and mortar but not the right neighbours
- Being able to cope with neighbours
- Responsibility
- Contact with landlords
- Dealing with estate agents

Within Scotland there are two very useful publications with reference to housing provision for people with Autism. In 2004, the National Autistic Society (NAS) and the Shirley Foundation produced a document, written by Maurice Harker and Nigel King, entitled *Tomorrow's Big Problem – Housing Options for People with Autism, A Guide for service commissioners, providers and families*. This document outlines the fact that much provision has been made for people with physical disabilities, in reference to housing and their desire to remain an integral part of the community, and how this was subsequently delivered to people with learning disabilities. It argues that this should be the case for people with Autism and that all local authorities and potential service providers need to recognise this as soon as possible, as the diagnosis rate for people with Autism is ever increasing. Values in the White Papers: rights, independence, choice and inclusion.

The document details a recent trend away from the institutional character of long term hospital and care homes to the provision of more ordinary domestic accommodation and to the facilitation of normal living. It goes on to state that:

“Those with a diagnosis of Asperger’s Syndrome often found difficulty getting help with housing and support. They did not meet the usual service definitions of need. Family or service provider help was often crucial, as well as the involvement of someone from local services who had a good understanding of autistic spectrum disorders.”

There are a lot of factors that need to be right to enable someone with Asperger’s to find suitable housing.

“The new agenda for services has all been about promoting independence, an ordinary home and social inclusion. A greater diversity of needs being addressed, including new approaches for those with lower support needs in their own homes.”

*Tomorrow’s Big Problem* then discusses the prevalence and issues faced when trying to access housing for people on the autism spectrum; it describes a number of case studies and models of housing and related support. It details autism specific service design – simple layout, space standards, serviceable and hardwearing materials, light, acoustics and noise, communication, furniture, fittings, equipment and furnishings, security and risk. However, the document argues throughout that all housing and support provisions should be person centred and individually led.

Glasgow Council also launched the first housing guide to support people with Autism on 16 March 2010. This is an extremely useful document that was produced in response to a questionnaire sent out to people with Autism and their families, with some input from housing associations, organisations and charities. Again, it does not distinguish between the various points on the spectrum. It is written as a good practice guide for Registered Social Landlords. The main specifics raised by the response to the questionnaire were a lack of separate bedrooms for childcare; access to a safe and secure garden; funding for adaptations; and neighbours. The document goes on to detail the provisions that must be made under the Disability Discrimination Act for people with autism. It outlines a number of recommendations on supporting people on the autism spectrum in a housing setting:

- Housing providers should consider alternative or multiple ways of communicating with customers on the autism spectrum.
- Local provision or adaptation of current residences are the best means of meeting housing needs and addressing allocation issues. A house move can lead to particularly large amounts of stress and anxiety for people with autism, who rely heavily on routine, structure and informal support, which relocation might undermine.
- This publication suggests that autism diagnoses should be shared with housing providers to help sustain tenancies, which might otherwise fail due to the potential invisibility of autistic spectrum disorders. These may not be initially obvious to housing officers or other professionals

- There should be clearly worded tenancy agreements in place, outlining the responsibilities within a property, and defining when faults should be reported and how.

The Environmental Service Standards outline a number of things that should be taken into account when looking at living accommodation for someone with autism. These are simple but effective guidelines on minimising the potential stress that could be caused in an environment. There are many areas of good practice in the provision of housing for people with Asperger's. A number of successful cases have been studied, but for each of these there are many instances of individuals on the autism spectrum being failed in housing provision.

*Some autistic people suffer greatly from noisy and unsocial neighbours and are at a loss on how to deal with them.*

*Some autistic people find managing a flat or rented accommodation difficult because they find housework, paying bills etc, difficult.*

*Some younger autistic people suffer in shared flat scenarios and experience exclusion and rejection from their flatmates.*

*Independence is really great when it works OK, getting used to the poor choice of housing and landlords is difficult.*

People with AS may use the internet instead of enduring supermarket shopping. Despite internet shopping being more autism friendly, however, the resultant deliveries may contribute to anxiety about visitors – what they want, what to say to them, how to get rid of them, will they close the gate properly? The issue of deliveries, unexpected callers and visitors intrude on feeling relaxed.

*These days I have a few friends and many acquaintances but I don't want to meet them in the flat nor do I want to meet them in their homes. Domestic environments and family setups make me feel either trapped or uncomfortable that I don't share a similar lifestyle. I like meeting in a neutral space such as an autism centre, café, museum, park etc.*

Sharing space, such as tenements or stairs, can be problematic for those people with autism who, for example, are insufficiently or excessively sensitive to various types of sensory information. According to the National Autistic Society:

*'People with sensory integration difficulties – including many people with an ASD – have difficulty processing everyday sensory information. People who struggle to deal with all this information are likely to become stressed or anxious, and possibly feel physical pain.'*

Issues with touch, taste, balance and body awareness ('proprioception') might affect the living circumstances of people with Asperger's Syndrome, but not nearly to the same degree as sight, smell and audio sensitivities. Visual sensitivities can cause issues with colour and lighting. Some people might not be able to cope with fluorescent lights, or need complete darkness to sleep – requiring blackout blinds. Other people might need to keep their curtains closed during the day, but this can

seem odd to neighbours. People with Asperger's might also have olfactory sensitivities. They may smell things which no one else can, or be physically affected by certain smells, including the smell of cooking. There was an incident with a local authority where a 'smell appeared in someone's house'. The tenant and regularly visiting support workers were aware of the smell, but workmen from the local authority could not detect it, despite ordering drain surveys and lifting floorboards. One workman eventually suggested that a polythene barrier be employed to prevent the smell pervading the flat. This method was agreed by all parties, but took over a year of arguing and visits to someone's home to reach this conclusion.

*I believe my housing solutions and preferences are strongly connected with sensory sensitivity issues particularly visual and noise stress. In addition, I would say people stress is a big factor. By this I mean that the prolonged presence of people, their voices, smells, movements, proximity and social initiations and demands can create annoyance and total exhaustion.*

People with Asperger's Syndrome can be hyper or hyposensitive to sound. In the context of living circumstances, this might mean that, as with smells, they can hear noises that other people cannot hear. There are a number of documented cases of people living in flats with upstairs neighbours with laminate flooring; this, coupled with the noise of a baby walker, has been known to drive people to distraction.

*People stress can also lead to sense deafness. By this I mean sometimes I feel forced to pretend that I know what people are saying but I become fearful that they will notice that though I hear the sounds they are making, I'm not making sense of what they are saying.*

People with Asperger's might find it difficult is in distracting themselves from on-going noise, which will fixate them and become the focus of their entire being. They will be unable to function for its duration. While there clearly is some good practice in accommodating people with Asperger's, it would seem that issues like sensitivities are very unique and need to be dealt with on an individual basis, with openness and sensitivity. Additionally people with Asperger's may be considered odd or suspicious for trying to keep themselves to themselves and to avoid unexpected or unplanned communication.

*In addition, I feel the private aspect of my adult life, in particular the absence of a partner, exposes me to negative and suspicious attitudes from others. To avoid these encounters, I've chosen at times to live in anonymous housing situations or selected flat mates who would be unthreatening and cause minimal sensory stress.*

*Following my graduation as a student and having independence with a career, my housing experience would become an even greater challenge in coping with the housing I've lived in and the neighbours there, because of repeatedly ending up beside antisocial neighbours. All too often indeed, they have been the sort of neighbours who get evicted or are in danger of it.*

One person with Asperger's was told by the police and council that no action could be taken without evidence of antisocial behaviour. So, when a youngster climbed into their garden and repeatedly kicked a football against their window, this was filmed on camera. The parents of the youngster took exception and proactively phoned the police, reporting the person for filming children – an accusation which can have many serious repercussions.

Many people with AS have high moral values and are very clear in distinguishing right from wrong. This can be difficult if it includes the reporting of noisy or anti-social neighbours who may then retaliate. Such genuine cause for concern must be addressed fairly:

*At this new address, a tiny one-bedroomed flat on the high street of a small town, there was only one other flat in the stair. But I'd walked straight into a situation where they were extremely noisy neighbours, with them and their friends loitering in the stair using drugs almost every day. This and other destructive behaviour went on until they were evicted. After that I lived in a period of peace, something unusual for me.*

*I eventually got back on the property ladder as an owner occupier, but what a mistake. It was by far the most traumatic living experience I have had. Again, a neighbouring flat was home to a very antisocial family, and youths loitered beside my flat (residents of neighbouring flat plus friends) almost every night, often drinking/smoking/drug using, usually committing horrendous disturbances. Vandalism on many occasions, even urinating in stair. I have had people waiting outside the flat with a baseball bat. I lived life in a complete, debilitating fear. I suffered severe mental health problems due to living there, especially as the situation never improved in over 3 years.*

This document covers the very basics of the complex problems which people with AS might encounter in seeking suitable accommodation for themselves. It is clear that some local authorities and landlords have got some really good insight into the relevant issues, but that this is inconsistent across the board. This article also highlights that suitable housing can only be sought and found on an individual basis – no set model will fit the whole spectrum or indeed two individuals.

*My major worry in living by myself is keeping the flat tidy since my housekeeping abilities and inclinations are minimal and with a leased flat there is always the thought of rent increases and possible eviction at the back of my mind. When I retire, possibly in about five years time, I feel my insecure housing situation will make me more vulnerable and I may become a reclusive and agoraphobic person.*

It should also be remembered that while the NAS recommend that discussions around accommodation for people with AS should be started at the age of 14, and be treated as part of a youngsters' transition, equally, like the rest of the population, people's housing needs change as they grow older.

Unfortunately it would seem that trial and error still needs to be resorted to, in successfully supporting people with AS to secure suitable accommodation, although the message is clear that all the housing options that are available to the rest of the population should be available to them.



### Reflective questions

- How aware are housing associations and estate agents in your area of offering sensitive and appropriate advice to home seekers who are on the autism spectrum?
- When a person with AS is a home owner or long term tenant is it assumed that all their housing needs are being met?
- If you are someone with AS do you share this with neighbours? If you are that neighbour how do you respond?



### Chapter 10 – Rights and Benefits

Self directed support, access to benefits information, advocacy.

#### **Cameo 1**

*Since being diagnosed I have been shocked that no-one has ever given me any information about rights and benefits. As someone who works I fully expect not to be entitled to any benefits, but there is a real possibility that I will be made redundant in the near future and it would therefore be beneficial to know about rights and benefits now so that I can access these if and when needed. Sadly I have no idea where to start with this issue and my attempts to find out information have been frustrating. The fact that no professional has ever contacted me about this simply adds to my feelings of worthlessness and insignificance.*

#### **Cameo 2**

*'I find it very difficult to approach people for help and most of the information is just too daunting and overwhelming – so I end up not doing anything.'*

#### **Introduction**

Whenever we discuss 'rights' it is usually in the context of 'what I am allowed to have'. For example, you can be allowed to have free speech, a place to live of your choosing, to vote in elections or to live free of discrimination.

But what happens when your rights conflict with those of someone else, if your lifestyle doesn't fit with or disrupts the people who live around you? With rights must come responsibilities, things we must do to ensure that everyone else can enjoy their rights at the same time as we enjoy our own rights.

So everyone has rights – and responsibilities – things they can claim and things they must do. But not everyone knows what rights or responsibilities they have, and not everyone acts in the right way. This also applies to organisations, which includes the Government, local councils, the NHS, police, voluntary organisations and businesses.

As members of society, people with autism can ask for help when they need it for themselves or for the people who care for them. Everyone is entitled to access services and financial support but often we find that people with autism are turned away from help because their condition, autism, isn't understood.

This might be because a person with autism finds applying for help too stressful or difficult to understand, or because when they are assessed for support they may need, they are turned down because the person assessing them does not understand their needs.

It is wrong that people with autism should be treated like this. Organisations and public bodies who support people have a responsibility to make sure that people with autism enjoy their rights.

*An assessment/diagnosis should be an automatic right for every individual who chooses to seek one, but the right not to seek one should also be respected and those who choose not to seek diagnosis should be respected. I accept that the latter can cause distress and upset for families and carers, but I strongly believe that the rights of the individual are paramount.*

### **Discussion**

Everyone, including people with autism, has the right to help and support that allows them to live independently if they need this help. This help can come in different forms depending on the nature of the need – for example financial, social, health or housing. Often people's needs are complex and help may be asked for from different sources.

This makes the benefits system very complex and difficult to understand and having access to good advice, or an advocate who can help you get your point of view across, is often needed.

In the UK there are nearly 50 different types of financial benefits available and these are categorised into two main groups – means tested and non-means tested. A 'means test' happens when your own income or resources are taken into consideration when deciding if you qualify.

*I think they should create new benefits for people on the spectrum.*

As well as being a highly complex system, the rules for benefits are always changing as the UK Parliament passes new laws. In recent years UK Governments have promoted the idea that benefits should do more to help people into work or to live independently. For those who receive financial benefits this places more responsibilities on them.

The great majority of financial benefits are available to everyone. There are 'Social Security' benefits and are administered by the Department of Work and Pensions (DWP). The DWP does not do this directly but through three 'executive agencies' (bodies set up by the Government) and these are:

Jobcentre Plus  
Pension, Disability and Carers Service

Jobcentre Plus is responsible for benefits for people who are of working age. This includes Jobseekers Allowance, Employment and Support Allowance and Income Support. It is focused on supporting people when they are not in work and helping them into employment.

The Pension, Disability and Carers Service provide financial support for people who have disabilities and their carers. This includes Disability Living Allowance (DLA), Attendance Allowance and Carers Allowance. It is responsible for providing the State Pension and other retirement benefits, including pension credits.

It is useful at this point to highlight 'tax credits'. Tax credits are an important part of the benefits system but they work differently from paying someone a benefit. Qualifying for a tax credit depends on your income level, if you have children, a

disability or receive a pension. People who qualify for a Tax Credit receive a payment separate from their income tax in the same way that benefits are paid.

All Tax Credits are administered by Her Majesty's Revenue and Customs (HMRC) who are also responsible for Child Benefit.

Finally, some benefits are administered by local authorities, also known as your local council. These include Housing Benefit and Council Tax Benefit. Councils are also responsible for providing many of the support services people with disabilities and their carers use including social work support, respite care and protection for vulnerable adults and children.

The way in which councils provide this support is changing. For a long time someone requiring a social service would have few choices about the care they received. Now they can have the option to direct their own support, called 'Self-Directed Support' (SDS). This is a new right for people and it allows them to have the choice to take the money that would be spent on their service as a direct payment, and to use this money as a budget with which to buy the services they wish to receive.

Self-Directed Support reflects a growing movement across all forms of support for people that places more responsibilities on individuals and families, but also gives them more rights by allowing them to make choices.

*Could do with some sort of pack given to people on diagnosis with all the information together rather than have to find out yourself as a lot can be missed out because you are just not aware of it. Some social workers did not seem to realise Asperger's is a lifelong condition and were not too clear on Self Directed support even though had just been on course. Some things they said differed a lot from information I had read, they said internet was not the best place to find information even though I had mostly been reading the Council's own website. Have not heard back since meeting.*

Support services provided by councils are often referred to as 'Community Care' as they cover help with daily living. The law entitles people with care needs to appropriate services and this often comes from many different organisations. Whilst the meeting individual needs and rights, personalising services and sustaining choice can be a challenge for services, every effort needs to be made to combat what is known as the postcode lottery.

*Living in the Highlands seems to mean that access to services and support is more limited than it appears in other areas of Scotland. Living outside a big city, and in a more rural area has its own advantages for me, in terms of my AS but is a disadvantage when I need assistance.*

Sometimes the support people need also involves their health or housing. The National Health Service (NHS) not only cares for people if they become ill, it also helps people to stay healthy. Health services are provided entirely on need, you do not need to pay for them.

Support for housing ranges from those who have high-support needs, for example for full-time residential care, through to helping people live independently in their own home.

If you are feeling confused or overwhelmed by the complexity of benefits available do not be disheartened because everybody finds it difficult to understand! Whatever the type of support or benefit a person with autism may be entitled to, they should always expect to be treated with dignity and respect. They can also expect, as a right, to receive help with any communication support they require in order to access or use services.

*The "benefit trap" is a major financial barrier when looking for future employment and the fears of losing out dramatically. I however have contact with the local welfare rights office and this reduces the worry.*

Many of the agencies that provide benefits now prefer people to access them using the internet or telephone services. They are also required to support people with different communication. Many people aren't aware that this help is available to them and it is very important for anyone who has autism and who wishes to access benefits or services to be able to ask for the support that they need. However,

*Practitioners still need to be experts in autism thinking and processing though.*

If this support isn't provided, or isn't provided in a way that actually helps a person with autism, then there is a barrier for them receiving the support and this must be challenged.

The Equality Act (2010) protects individuals from both direct and indirect discrimination. Direct discrimination happens when someone denies an individual their rights because of an attribute they possess, for example because of their disability, ethnicity or sexuality. Indirect discrimination is said to have happened if the policies of an organisation lead to someone being denied their rights, for example denying access to childcare.

The Equality Act says there are certain 'protected characteristics' people cannot discriminate against, including race, gender, sexuality and disability. A person with autism, or any other condition, is protected if they are discriminated against because of their autism by the disability characteristic. However, people who have autism are also protected if they have any of the other characteristics as well and if they are discriminated against because of their race, gender or sexuality.

Having a 'protected characteristic' means not only that you can expect to be treated fairly, it also means that government policies and practice have to take into account what impact they will have on your rights.

So how can people with autism best protect their rights?

Every organisation covered by the Equality Act is expected to have an equality strategy which you can read. Having policies is only the start, people in organisations also need to know how to apply them.

We have already said that people with autism are protected because they have a condition considered to be a disability. This is agreed in law but many people still don't understand that autism, because it is not a physical disability, is still included.

Many equalities and disability policies don't address the needs of people with autism because they are not written by people who know about or understand autism.

This can unhelpfully allow for discrimination to take place and people who care about autism need to make sure that organisations have the right policies to help them. This can be done by meeting with the people who have responsibility for equality law and asking them to review their policies. Doing this also shows that people with autism are playing a responsible role in helping to improve the rights of everyone.

It can be difficult understanding all these different systems. There are many points at which a person with autism, seeking help and support, may fail to communicate what they need.

It is very common for people who are carrying out an assessment to have no understanding of autism and this can lead to unhelpful or even completely wrong assessments being made. If this is the case then it is important to remember that rights don't end when a decision to reject a request for help is made, there is always a right to challenge a decision felt to be wrong and these rights don't have to involve taking legal action either.

As well as equality policies every organisation must also have a complaints or appeals system and the same support that should be available for accessing benefits or services should also be available to access these.

There are often locally based forms of support that can help people to access support, for example Welfare Rights services, benefits advisers and advocacy services. These services exist all over the country and are there to give individuals who may have problems getting support such as benefits. People who act as advisers or advocates are independent of the bodies that take decisions and most importantly do not make decisions themselves. Their role is to help the person applying for help.

*Have had to access Advocacy in past to help with a work issue, It was a case where my behaviour had been part of a grievance procedure (quite wrongly as it turned out) However my saying that I was seeking an advocate threw the whole process into disarray.*

More unusually people with autism are beginning to self-advocate: there is also a strength in a collective approach:

*Creating understanding and tolerance for people with autism is most important. Here in the Highlands this is being done very successfully by members of the Autism Rights Group Highland (ARGH), which is made up by adults on the autistic spectrum, including myself.*

*I only know these things because I chair an autism rights group and we inform our members; otherwise I wouldn't.*

*Well, the best is our own Autism Rights Group, run by and for autistic adults, which provides collective advocacy.*

### Summary

Autism is presenting a real challenge to state welfare services. As an 'invisible' and 'complex' disability it presents real difficulties for decision makers who have little or no awareness. The types of help that people with autism need, including the 'reasonable adjustments' required by law to allow them to access goods and services, are often not planned for or made available.

People with autism need to enjoy their rights just like everyone else, but it can be difficult for them to understand when they are being discriminated against as they don't always know about their rights and responsibilities. This can leave them in a very vulnerable position. The stress and anxiety caused by going through difficult application procedures and assessments causes many people to stop engaging and contributes to their isolation.

The solution to this is for people with autism to work with public agencies to improve their knowledge and understanding of autism. People with autism also need to know what rights they have and to be supported when they need their rights protected. At the end of this publication there is a list of resources they can use.

### Reflective questions

- Individual aspirations for work and housing can be affected by fear of making any change to the status quo: how familiar are you with supporting individuals who wish to make informed choices about seeking work, and how this may affect their benefits?
- Some care and benefit assessments take place in people's own homes: how might people with AS be supported to cope with the anxiety and intrusion?
- As a person with AS could you offer to raise awareness amongst professionals about your perspectives?



### Chapter 11 - Growing Older

Growing Older heralds life changes in health, getting out and about, employment and retirement, bereavement, caring for relatives, avoiding loneliness and planning for the future. Many of the issues raised in other chapters take on a new focus as people grow older.

#### Cameo 1

*The fact that I have so few landmarks in my life (no marriage, children, significant achievements and so forth) makes growing old very difficult. There is very little for me to look back on and aging gives you less and less to look forward to. I have always struggled to plan ahead and so the concept of preparing for retirement and old age is beyond my understanding.*

*I already struggle with personal care and, although I can keep myself reasonably clean, keeping the house clean is beyond my abilities and I am left in a situation where I am thoroughly ashamed of my home and the squalid way I live. Without any support I can only see this getting worse as I get older which will not only lead to me feeling worse and worse about myself, but will add to my isolation as inviting anyone to my home would simply be humiliating.*

#### Cameo 2

*Jim is 51 years old. He was diagnosed with Asperger's syndrome (AS) as a child, but only found out about his diagnosis when he was 26, by this time he had achieved a university degree and had been in successful full-time employment for 5 years. In 2011, he is still enthusiastically working for the same employer. His father and grandfather both passed away in the early 90's; after this Jim moved into his grandparents' house along with his mother. Sadly she also passed away in 2008 and since then Jim has been living alone in the house. He could not face touching any of his mother's belongings for a long time, but more recently he's managed to start clearing out the house: he describes this experience as being 'an emotional rollercoaster'. Jim has two brothers – one lives in London and the other in Scotland. He looks forward to seeing them and their families in the holidays. After a traumatic relationship breakdown in his 20's, Jim was put off entering into another one, and 'never met anyone that came close' anyway. Children were never on his agenda, so he doesn't feel as if he missed out here, however Jim says that he is definitely at risk of getting lonely.*

Growing Older with Asperger's syndrome is a vastly under-researched topic. Because Autism was only recognised as a condition in the UK in the 1970's and Asperger's has only formally been recognised since the 1990's, there has not been much opportunity for research into how growing older affects these individuals socially, economically and in terms of their physical and psychological well-being.

Jim's story highlights that individuals with autism are normally dependent on their parents for psychological and emotional support until later on in their lives. This is probably because their social networks are limited in other ways. Whereas 'neurotypical' people tend to form relationships and have their own families in their 20s or 30s, individuals with autism often stay single and therefore retain close ties with their immediate family, rather than establishing ones outwith this network. Many individuals with autism tend to stay close to home rather than moving away when

they become adults. Again this may be due to limited social opportunities, but may also be linked to dislike of major change or disruption in their lives. Also, the security of having close family who will understand and support you no matter what is bound to be an important factor. Cameo 1 particularly illustrates this isolation, lack of self worth and anxiety about growing older.

People with autism tend to enjoy routine in their lives. Jim's main supports are the local Asperger Society, the local service provided by a national autism charity and his church membership. A support worker from the autism charity has been coming out to see Jim once a week for the last two years. The initial objective here was to ensure that Jim was preparing healthy meals at least once a week, but Jim now finds that this support is more about having 'nice company' once a week. Jim also sees a volunteer befriender once a week: they usually go to the cinema together.

The combination of work and such support allows a balanced, enjoyable and fulfilling life. This is not always the case for people with AS, particularly as so many experience difficulties in getting into and retaining employment. Without employment (or regular voluntary work), it is hard to find structure in one's daily life.

In this respect, Jim regards himself as being extremely fortunate, and is grateful to his parents for not telling him about his diagnosis until his late twenties, by which time he had established a good career. He feels that informing his employer about his diagnosis at the time of applying for his job might have altered their perception of him and may have resulted in them deciding to not take him on.

Jim has lived a particularly independent life. This seems to be fairly common in individuals who were diagnosed with autism later in life (or only discovered their diagnosis later in life). It is almost as if they had no other option but to 'get on with it' and carve out the best lives they possibly could with limited support. This also means however, that some people on the autism spectrum will have spent years 'suffering in silence', perhaps not coming to terms with their diagnosis, or understanding why they found certain tasks more challenging than others, particularly with regards to forming relationships:

*I fear when I retire I will become a recluse. The work environment keeps me in socially active state of sorts.*

*I fear when I get old that I will be vulnerable to manipulative people. Isolation and decreasing social skills will make this a possibility.*

Although Jim needs a degree of routine in his life, he has enjoyed bouts of travelling solo over the years, although one particularly bad experience on a group holiday a few years ago was enough to put him off trying that again. Some people with AS require such a high degree of regularity and routine in their lives that they would find moving cities or going on holiday far too stressful. Jim seems to have the balance right in that he has been able to maintain a successful career over 30 years and have regular breaks away to satisfy his need for stimulation, although he comments that he often wished that when he was traveling he was more able to spark up conversation with other people. Loneliness can be a common denominator in all areas of life with AS.

*I dread growing old and especially thought that I have no family. I imagine I will be very lonely as likely to have even fewer friends than I have just now.*

Other members of the SASN Asperger's Forum felt that 'being able to pass on intellectual capital' was a concern for them. Jim didn't feel that this was an issue for him as he enjoys spending time with his brothers' children and is able to pass on knowledge and experience in this way.

Another issue that was raised by multiple members of the Forum was 'looking after oneself and managing on one's own'. Able individuals with AS may nevertheless have difficulty with daily routine tasks, with running their home, dealing with paperwork and making their own meals – for others preparing for a community care assessment that means allowing others into their home causes huge anxiety – sometimes because they are not coping, but also because of prevailing concepts of disability: having a full fridge and a tidy home may belie the true nature of an individual's difficulties.

As chapter authors we discussed this and Jim feels that he is managing okay at the moment, but he does worry about what is going to happen when he retires in 9 years. His competence and independence comes of years of routine and is worlds apart from the concerns expressed in Cameo 1. However managing such routine has its burdens and Jim thinks that he may even have to retire a little early or he may be 'let go' early because he will probably be 'deadwood' in a few years. Like others Jim's main fear is isolation. He says he may take up voluntary work at his Church or at an Autism Service to keep himself busy – Jim values the routine of full-time employment hugely.

Finding appropriate social opportunities as age and your own circumstances change raises concerns for many who value a sense of belonging and making social contacts:

*When I'm too old to be in groups for the young, at 40+, I still don't want to be pushed into groups for the old, which still have much older members who may have hurtful views against my generation and era.*

*I am an Aspie but not interested in the virtual world. I want to socialise in the real world.*

Age often brings a need to reconsider living arrangements. The thought of moving house is anxiety-inducing for anyone, but for someone with AS it is potentially terrifying. This kind of drastic change would require long-term planning and support from other people.

Although Jim says he is managing okay at the moment, he is aware of the fact that he has been left to cope in his grandparents' house, which was never really part of the plan. He dreads the idea of having to get any work done on the house as he is fearful of tradesmen due to past experiences. He faces the dilemma of whether to move out into somewhere more manageable, or to stay in this house which may require maintenance over the years – the alternative is moving house. Jim does not know if he could cope with such a task. He says he hopes he is never dependent on

social services as he 'wouldn't want to be a burden'. He feels that if he had to move out of his current home, he would want to go somewhere sheltered where he would get the right support.

Some members of the Asperger's Forum expressed concern about declining faculties. This is not something Jim has thought about much himself. He acknowledges that he is not quite as fit as he used to be and that maybe he should pay more attention to this.

Taking on a caring role, for example having to look after a parents whose health is declining brings about major change and the loss of valued activities such as regular recreational classes, walking holidays or sport. Bouts of depression can occur and these may be triggered by life events, such as relationship breakdown or changes at work. The concern that health problems related to ageing could possibly trigger depression again is a common anxiety.

Some members of the Asperger's Forum expressed concern for the future of the earth. This is not something that all dwell on regularly, though Jim mentions that it was a particular preoccupation of his mother.

Autism is a lifelong condition, learning, development and change are also a lifelong activities. Although growing older can bring many challenges so too there can be a sense of finally growing into yourself. A senior member of our Forum ponders this:

*Three score years and ten - a year stone, a figurative peak, am I now a wise old owl?*

### Reflective questions

- The issues raised in this chapter affect us all: have you considered the ways in which people with autism may be particularly vulnerable as they grow older?
- What could you do to help people with AS find the social supports and friendship groups they wish for?
- What ideas do you have for supporting the person with autism who has become a family carer both now and when that caring role comes to an end through bereavement?

### Chapter 12 - Virtual Worlds Using Digital Technology

It may be thought that because a person with autism may not communicate easily with others that the digital world offers an alternative. Together we have begun to consider ways in which digital technology can contribute to individual well-being, but we are learning this is not always the case. Here we present personal experience and have yet to explore the literature on this topic.

#### **Cameo 1**

*I much prefer to type than talk. I don't use the phone at all; email gives me a voice rather than relying on someone else to talk for me. Online I can meet others and network. I can talk about daily life, autism rights, education with other autistic (and typical) people all over the world. It means that I'm not isolated, it means everything to me. When I can't go out to socialise I can still have contact with other people. If I lost the internet I don't know what I'd do.*

#### **Cameo 2**

*Because of my isolation, and because I'm technologically minded, because it's by far the most cost effective medium in my location, because I'm getting forgetful, and because it doesn't impose the same quick-thinking time constraints on me like phone calls and face-to-face talking do, I use it for almost everything. However I'm aware that spending too much time on the keyboard every day isn't healthy, and I wish I could find some healthier alternatives to achieve the same results.*

#### **A different kind of communication**

As the whole of society gears up to high speed virtual access, to managing bills, banking and shopping online, to logging in to Facebook, Twitter and other social networks as well as constant use of mobile phones, blackberries and iPhones, it can seem that the whole world is wired and that technology is a friendly giant. Rather than being seen as a tyrant, technology is usually seen as a benefit.

It is sometimes assumed that all people with AS are intrigued by technology and that many are technically gifted: we discover this is not always the case:

*I only really use the internet for work, and this is a necessity. I find it easier to write to people rather than talk to them. I do not have a computer at home and do not know how I would pick one or set it up.*

*I am slowly mastering digital technology but I make frequent mistakes and cannot understand computer jargon.*

*I am sure this is a very useful tool for many on the spectrum, but I really struggle with digital technology.*

Equally for many there is a sense of mastery in this arena:

*It suits us because it's governed by logical rules, and as long as we use our aspie perseverance to study how it all works, we can control it. Very much a refreshing opposite to how we view people and relations in the human world.*

### **Easing social contact**

The virtual world of the internet can serve us well. It can help with day-to-day chores and offers a welcome respite from making phone calls or face-to-face contact.

*NTs should be made more aware that digital technology for ASC is like a white stick for blind or wheelchair for the disabled – it is necessary to work and live.*

*I have most of my shopping etc delivered to home – this means no stressful trips to shops and access to more than I would have if going out. I am also more likely to be able to sort other problems out i.e. bills etc (using email rather than talking on the phone, or in person).*

*Much easier to email than use phone. My preferred method of communication as don't have to speak to people.*

### **Gives more time**

Information processing, gathering together what you want to say, responding to others' expectations and managing the timing involved in day-to-day communication can add pressure and cause frustration. Email and other virtual communications can allow more time to focus and get things right, and can therefore be more personally satisfying.

*With email I have time to think and a record of it, I dislike using phones as I have trouble making out what people say on phones and don't remember very well.*

*It gives me time to think - I don't need to see or meet people. Written replies etc are easier to take time to think about.*

### **Online social networking**

Our group members meet because they want to, because it's the scene and to spend time with other like minded people: but such opportunities can be infrequent. The arms' length contact afforded by the internet supplements direct social contact for some and conveniently replaces it for others if they can't go out to socialise.

*Greatly improved quality of my life and improved my behaviours caused out of things in the past.*

*I much prefer to type than talk. I don't use the phone at all; email gives me a voice rather than relying on someone else to talk for me. Online I can meet others & network. I can talk about daily life, autism rights and education with other autistic (and typical) people all over the world. It means that I'm not isolated - it means everything to me. When I can't go out to socialise I can still have contact with other people. If I lost the internet I don't know what I'd do.*

*I don't look at it or take part in the more popular 'rooms', my children have but they feel better on the more 'interests' type sites as everyone there seems to be the same as them.*

For some the companionship of shared times with others is irreplaceable:

*The glare of the screen hurts my eyes and the electronic background noise hurts my ears. Also, computers often don't do what they are told and I don't feel they are safe*

*either. You can only communicate with words, whereas I prefer to be with a friend and do things together. I don't have internet at home.*

*I feel at a disadvantage. Use it under duress.*

### **Cyber- bullying**

As in the social world there are risks of vulnerability, bullying and harassment. The written word can equally be misunderstood, hurtful or over direct. There may also be a risk that in the virtual environment one doesn't have to consider another's perspective and so postings risk being satisfactory for the person that makes them, and uncomfortable for the person who reads them. There are a range of views on such matters.

*Any problems I have with people online are greatly outweighed by the ease and readiness of the technology.*

*When a factional on line harassment issue was reported to the police, they turned it into a "fit and proper person" issue and said it's a civil law for a solicitor to investigate: the police don't get involved.*

### **Possibilities**

Individual taste and interest plays a part in how technology is viewed – for most our Forum members it is often a positive asset that has afforded new opportunities.

*Great to have an email mentor service so we can ask our daft questions and what next questions*

*Emails are a massive plus in terms of communication in terms of work. You have time to think your words carefully before posting them.*

*I know several aspies online who post heavily and are very social in an online sense, but who choose not to meet the people they post to in real life.*

*I enjoy the digital world. I help moderate an Asperger forum and enjoy meeting the members from all over the UK.*

*Often much easier for people affected by AS to communicate online as many elements as conventional communication are eliminated – eye contact, "real time"*

There are a number of research studies which explore the potential of digital communication for the autism population: many are at an early stage and focus on learning support. We conclude that more knowledge about the uses of digital technology and virtual communication made by people with AS is needed.

### Reflective questions

- Have you made any assumptions that people with AS might prefer virtual to first hand communication? Can you offer help to people you know to enjoy and make the most of both?
- Bullying and harassment can occur in all walks of life: how can society ensure that participation in online communication causes no harms?
- Do the potential benefits outweigh the possible risks?



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### Useful Links

Scottish Autism Service Network

<http://www.scottishautismnetwork.org.uk/>

Department of Health - Fulfilling and rewarding lives: the strategy for adults with autism in England

[http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_113369](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_113369)

iwork4me (Launched 21 September 2011)

<http://www.iwork4me.org.uk/>

Social Care Institute for Excellence (autism section)

<http://www.scie.org.uk/topic/careneeds/autism>

Self-Directed Support Scotland

<http://www.selfdirectedsupportscotland.org.uk/>

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