An Ordinary Life Too

Living Life to the Full Needs, Rights and Aspirations

2nd Edition 2016

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Acknowledgements

This second edition of An Ordinary Life is the result of a lot of discussion and hard work by the members of the Autism Network Asperger Forum. This group met 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. A small group of volunteer editors has worked on pulling contributions together for this 2nd edition: Maurice Frank, Mark Keenan, Harry McCormack, Lynne Moffat and David Seagrave. Aline-Wendy Dunlop and Maura Lynch have provided encouragement, help and food. 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, Ewelina Rydewskas and Jayne Porter’s work supporting new writing during 2013 and 2014 and Charlene Tait whose idea inspired this writing project.

The Writing Group has been made up of members of the Forum, with contributions from their invitees from Edinburgh and Lothian Asperger’s Society (ELAS), Borders Asperger and Autism Support Group (BAGGS) and Autism Rights Group Highland (ARGH) and for the first edition, associated professionals who were invited by the Forum members to take part. All concerned gave their time, knowledge and enthusiasm freely. We hope that this edition of ‘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. In preparing this edition we have drawn on written contributions from the wider AS Forum’s work during 2013 and 2014 (unless specifically asked not to do so) and set up a new online questionnaire to allow further and more recent contributions to the publication which has benefited from these contributions. The cameos are drawn from life but are sometimes composites rather than individual experiences – in this way we hoped to represent life with AS. The 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 to inspire change.

We include in our contributors list all those who contributed to both the original edition and the current one and expressed a wish to have their contribution acknowledged. Thank you all: this is your publication.
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Overview

Following a meeting to which any existing Forum members who had expressed interest were invited, a small Editorial Group of 7 people was formed last year, in order to produce a contemporary second edition of ‘An Ordinary Life’. We are all volunteers.

The Editorial Group invited autistic adults living in Scotland to contribute to this process by completing an online questionnaire presented under 17 chapter headings. We have updated the chapter titles to reflect new chapters that have been developed and include already published writing from the 2011 authors. Similarly writing is included from 2013 and 2014 workshops unless any writer specifically requested otherwise.

The background to this invitation is that, in 2010-2011, members of the Asperger Forum set up originally by SASN, were involved in the Adult Autism Health and Wellbeing Project. The project facilitated AS Forum meetings that met in Glasgow, and this group identified topics that were important to their health and wellbeing. The topics were used in the original questionnaire that was circulated to AS Forum members, their contacts and two organisations - ELAS and ARGH.

Notes from the Forum group together with information collated from the questionnaires formed a publication to give a voice to autistic people in Scotland. Each chapter was co-written by AS Forum members and an associated professional. As chapters in the first edition of ‘An Ordinary Life’ were limited to approximately 2000 words, it was not possible to include everyone’s comments on every subject but hopefully ‘An Ordinary Life 2’ (2nd edition) will add to information on the everyday issues facing autistic individuals.

There are many important messages and reflections in Ordinary Life Too. Five years on from our original publication too many of the issues then raised still persist. In this edition we therefore revisit persistent issues, introduce new perspectives and celebrate the achievements of autistic people and their activism in contemporary Scotland.

We hope our work reaches a wide audience of autistic people, professionals working in the field of autism, families and carers.

The importance of dignity and dignified roles in life for autistic people is the central message in this publication.
Chapter 1 A Good Start in Life

Whilst ‘An Ordinary Life’ focuses primarily on adult life, its contributors also reflected on childhood experience.

For any child their early years are a time when key foundations are laid - through experience, learning and relationships. This then forms the framework with which the young person begins to make sense of the world and progresses to embark on an increasingly independent and sophisticated life. The nature of autism as a condition however, means such formative life experiences can differ markedly from what would be regarded as ‘typical’, and thus ‘making sense of the world’ often results in substantially different understandings and perceptions to that of the mainstream population.

Although, undeniably, this can lead to challenges for the child it would be incorrect to portray childhood as a solely negative time for those with autism. On the contrary, those consulted were often able to recall positive experiences of their childhood too. Some such memories included:

‘Being taken out for a walk in the sunshine’

‘When I was four I started having horse riding lessons, I loved them, usually I was led down the cinder track by someone riding a tiny skewbald pony called Arkel, he was very cheeky and I loved being with him and the other horses.’

‘Getting a crossbar on my dad’s bike going to my grandparents’ years before he learned to drive.’

‘Spending time with my grandfather (father’s father) watching animal documentaries’

‘Lying awake at night, listening to foxes and owls and trying to teach myself how to write long numbers (I’d have been about 4 years old); reading; visiting elderly relative who was my pal, she coached me in singing and I won singing prizes at school as a result that was at about 10/11 years old’
From the selection of comments above, and from a wider knowledge of autism, it is apparent that enjoying life outdoors and being around animals is a common theme. Many people on the spectrum talk of having an affinity, or a love for animals and nature, and this may go some way towards compensating for feeling a lack of connection they say they often feel with other human beings. Temple Grandin is an example of autistic female who has used her remarkable understanding of animals (particularly farm animals) to vastly impact the cattle industry and the way in which these creatures are handled.

Despite recalling favourable times growing up, most of our respondents however, also remember realising, at various stages of development, that they were different from their peers and that their perception and ‘take on things’ deviated from that of others - often quite significantly:

‘I never knew what to say or how to play games and always seemed to have less physical ability, as in being behind my peers in things like learning to swim and ride a bike. I had a very vivid imagination though and could create hugely complex scenarios, preferring to play alone. (sic)’

‘I think I always knew that I didn’t fit in from the very start, over time I realised I just couldn’t understand they way they did things or why. They seemed logical (sic) and inconsistent and very unaware of things around them. (sic)’

‘The most intense feelings that I had as a child were feelings of being worthless and unwanted, and more specifically being nothing but a burden to my parents who saw me as a nuisance and inconvenience.’

‘I can’t really answer that; I don’t think I ever did really, although I went through a period of being bullied and another of not being allowed to join any groups at school. But I also had 2 sisters and for most of my life I’ve had at least a couple of people I’ve thought of as friends and often and since I was 16 I have had real friends, so I didn’t really articulate any idea of being different as such. I do remember writing in my diary when I was about 14/15 that I felt as if I was not a part of the world really but watching the world through a sheet of glass’

‘I also have very strong memories of my parents, teachers and other adults in my life constantly comparing me to other boys and persistently asking me the question “why can’t you be more like...?” as if I should be able to provide some coherent answer.’
'I always felt like the outsider looking in at others and being puzzled by the ease with which they could interact, the pleasure that they got from playing games together and the way in which it bonded them to each other.'

Many people state having an avid interest in facts and the pursuit of knowledge over social or generally less concrete topics:

‘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.’

With greater understanding and willingness to accommodate these and other differences associated with autistic processing, perhaps some of the difficult experiences recalled below could have been lessened and the resulting anguish alleviated. Individuals stated:

‘[They] couldn’t catch a ball’

‘Sometimes feeling very sad for no reason I could identify, crying and getting into trouble for being miserable / ungrateful’

‘Even as a very young child things in my room had specific places and I would get very distressed if they were moved, the same applied to the rest of the house, particularly the furniture, my Mum was one of those who was constantly rearranging stuff and this was very upsetting.’

‘I have always struggled with relationships and friendships’

Many find preschool educational environments and school itself an extremely challenging experience and again these are times when autism related issues became apparent:

‘At nursery in the play area there were lots of different activities to do and I remember that whenever someone joined me, or tried to play with me at an activity I would move to one that
there was nobody at, I hated the other children, I didn’t understand them, they were noisy and
didn’t take care of toys like I did, at home if anyone visited I would put my toys away so they
couldn’t spoil them. It was really distressing to be amongst them.’

When asked about starting school one person recounted:

‘......the school was at the top of our street and my Mum walked me there, I was quite excited
as my Dad had told me I would get to learn to read and write, but when we went in to the
class room it was full of other children and toys, we were each shown a drawer that was ours,
which was identified by a sticker, mine was a red butterfly, we were then shown our peg in
the cloakroom which was also identified by the same kind of sticker, My Mum was wearing a
long dog tooth patterned coat with a belt, when it was time for mum to leave I hung on to the
belt and screamed, I remember my fingers being prised off the belt by the teacher and my
Mum being told to go while I was held by the teacher. When I got home I was really upset with
my Dad because we hadn’t done any reading or writing and I didn’t want to go back, that was
the start of a long battle.’

Another said: ‘I was very confused and did not understand what was expected of me but no-
one was telling me what to do. It was assumed of me that I’d find a place to sit but instead I
stood aside and waited for the cluster of people to settle and awaited someone to tell me
where to sit.’

And a third: ‘Unfortunately my experiences at nursery school then went on to set the pattern
for the rest of my time in the education system, and my inability to know how to respond in
many circumstances continues to this day.’

Of all the autistic adults who contributed to this publication the vast majority were diagnosed
in adulthood. As a result, many of these individuals feel they have potentially missed out on
the kind of help and support that we hope is increasingly being made available to children with
autism nowadays. In addition, for most of their lives, those with late diagnoses, will not have
been able to benefit from initiatives and drives to enhance societal recognition and
acceptance. It would be nice to believe that such campaigns are increasingly chipping away at
misunderstandings, misperceptions, myths and prejudices out there about the nature of autism
and how it presents; thus ultimately widening acceptance. Receiving a late diagnosis can also
leave many feeling bereft at not previously having had a cause - or any form of explanation - to
attribute their differences to, despite searching for many years.
Although the above indicates a leaning towards favouring early diagnosis, it was suggested, that the downside of this can be that ‘your identity is autistic’. This may mean that rather than being viewed as ‘you’, you are viewed - by yourself and/or by others - through the label of autism from the beginning of your life. Unfortunately this can result in discrimination and/or limitations being placed on what you are capable of achieving from a very young age. Therefore, with hindsight, although for some people we talked to, early diagnosis could have been positive, for others ‘growing up in blissful ignorance’ is still likely to have been preferential.

The concerns referred to in the previous paragraph are hinged around the (largely) negative connotations and implications the autism diagnosis can bring with it.

‘I knew I was different, but only realised I was wrong in my late teens’

Although there have been drives to promote the condition as a difference, rather than a deficit, far more requires to be done. Encouragement (and possibly incentive) needs to be given for strengths, talents and abilities to be recognised and harvested, or labelling may more often than not lead to limitation and low expectation. Autistic people’s abilities are likely to be capped both in terms of their own thinking and that of those coming into contact with them.

A desire to be recognised as different, not less, is a publicised tagline and this idea is acknowledged by the autism population in comments such as the one made below:

‘To be accepted for the things they [we] do, not to be forced into some kind of acceptable mould. To be helped to use their strengths to cope with the world around them and to be believed even if they can’t explain why something is.’

Retrospectively, autistic individuals can often see in their own lives where encouragement of natural proclivities would have been valuable:

‘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. I wish the teachers had encouraged me with that instead of sneering.’
Despite differing perspectives on early diagnosis most people within our group thought that in order for the impact of the current move towards early recognition, diagnosis and intervention to be realised it would take some years yet:

‘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.’

As stated at the outset of this chapter, childhood is a key period in a person’s life, the impact of which is fundamental to who you become and this is also recognised and acknowledged by the adults within the autism community itself.

‘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 approach and attitude of others, what they say about you, and what they encourage you to do are all shaping factors of childhood experience. A supportive, understanding and positive approach at a young age is key to cultivating self-esteem and healthy psychological development. Conversely, lack of acceptance, chastisement or ridicule will generate and enhance tendency towards negative, destructive and resentful behaviours towards self and others in the years ahead. This is one of the reasons why a child with autism or another neuro-developmental difference should be identified as such (i.e. as thinking, processing and generally experiencing the world differently) - and not purely dismissed as defiant, obstructive or ‘naughty’ when they cannot conform.

Ultimately, we would hope that the present-day increase in recognition will prove to be advantageous and lead to both children and adults receiving greater understanding and support, consequently resulting in enhanced, more fulfilled and happier lives. Additionally, there should be a greater push for all individuals to be encouraged and taught from a young age to accept and respect others as they are and appreciate that many people are markedly different through no fault of their own.
Reflective Questions:
For the person with AS: The perspectives shared here underline the importance of increased awareness and well informed responsiveness to autism in early childhood as the beginning of a lifelong journey: could you use these examples as you seek greater understanding of autism?

For the parent/carer: What can be done to ensure recognition of a family member's autism is a positive process and leads to new opportunities?

For the professional: Do any of the points above help you to understand and respond to the people with AS you work with to a greater extent?
Chapter 2  Diagnostic Issues

This chapter focuses upon diagnosis and health and wellbeing therein. We discuss some of the issues surrounding diagnosis of Asperger syndrome, or more ‘able’ autism in adults. These diagnoses are increasingly being combined into one higher ability autistic spectrum diagnosis in wake of the DSM 5. Consideration is given to both the negative and positive aspects of the process, as well as potential longer term implications for the individual. Reference will be made to personal experiences with the aim of providing meaningful insight.

Individuals seek a diagnosis for a variety of reasons. This may include a need for recognition (and perhaps, to an extent, validation) of their social differences - this often follows a history of significant mental health issues and/or problematic life experiences.

The decision to pursue a diagnosis may come about after finding and relating to the Asperger scene. Going forward, a person may feel better understood by having or offering the diagnosis as a way of explanation.

It is common now for children to be identified as being on the spectrum and one (or even both) of the parents to identify traits or characteristics in themselves. This can then provide them with an explanation as to why aspects of their own lives have been the way they have for them. They may then decide to pursue a diagnosis for themselves, and/or may use this self-knowledge in some other way to adjust their life for the better.

Commonly, people seek to acquire a diagnosis to feel in a stronger position to access services - which are inaccessible without the diagnosis.

The following quotes state why people have found having the diagnosis beneficial.

‘I strongly believe that everyone who wants a diagnosis should be able to get one. A diagnosis is essential to helping you to understand the person that you are, why so many basic things like socialisation are extremely difficult and why the world treats you differently. A diagnosis can be the first step to accepting yourself as you are and accepting that if you want to have anything resembling a happy life you need to concentrate on being yourself and not trying to be the person you believe society wants and expects you to be, trying to be someone you’re not will always leave you feeling empty and shallow.’
‘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.’

‘It explains a lot which was previously put down to being bad / awkward / stupid / lazy / having no personality / not trying.’

‘Having ended up in the mental health system 15 years before diagnosis it has eventually helped them [family] and me see some of the difficulties in a different light, it has meant access to more targeted support and put me in touch with others like me. I have stopped continually beating myself up over things I can’t do like other people.’

‘Unfortunately in today’s society it is often the only way to access help and support, but also because for me it has helped provide an explanation of why things are the way they are for me, helped me feel less bad about myself for not being able to do things like most people and helped me find solutions to problems too.’

‘A diagnosis opens up an avenue to seek support.’

‘A diagnosis changed everything - things started falling into place in terms of where to seek support.’

‘I’m not invisible anymore.’

‘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.’

‘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.’

‘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 those who choose not to seek diagnosis should also be respected. It can cause distress and upset for families and carers, but I strongly believe the individual’s rights are paramount.’

Despite the above, pursuing, undertaking and gaining a diagnosis has been quoted as ‘a risky business’ - not without its pains. How then does an individual and practitioner ensure a safe experience of diagnosis, if the longer term benefits are to be gained? This is a concern many with an investment in the autism community regard as an important question.

Members of the initial SASN Asperger Forum and those within the survey pool told of attending Asperger groups as a lead in to diagnosis. They often found that meeting others with diagnoses ‘helped their own journey’. This mutual support is commonly found by joining a group where it is safe to divulge how you are, and indeed who you are. The value of this contact is also frequently reported amongst the female orientated autism group Scottish Women’s Autism Network (SWAN). For a considerable number of attendees it is likely to be the first time they have met others that strongly identify with the issues they themselves have faced all their lives and with whom they find they share many common traits and perspectives. Too often people with autism feel unable to disclose their diagnosis - or pre-diagnostic concerns or issues - amongst family or in the workplace for fear of the consequences. Responses are mixed.

‘I have tried to explain to them but my 2nd daughter has a 1st in psychology and I STILL don’t think she gets it.’

‘Much of my childhood and adult behaviour makes more sense to them [in relation to his family].’

‘Once you have an official diagnosis there is no going back and the concern about how people would react if I told them was hugely worrying for me. I only went for a diagnosis when my life reached crisis point and I was so distressed that I was struggling to cope day to day. As it turned out it was a very positive experience... I had to reach a further complete crisis point before I was ready to tell anyone in my family. First telling my friend, and none of my fears
had come to pass, understanding and keen to be supportive, was the crucial turning point, to be more open with others.’

‘My husband coped very badly and it was just another weapon for him to beat me with. If I had to go back again I would not have told have told him.’

Some people reading this may be familiar with the Neurodiversity movement. This is a social justice movement which challenges the medical model’s portrayal of autism, and other conditions such as dyslexia, dyspraxia and AD(H)D, as pathological - instead promoting them primarily as differences in processing and understanding, which only really become barriers as a result of the way society is fashioned. Proponents of this movement aim to promote societal change - namely acceptance and inclusion to accommodate neurological variances and seek to significantly reduce endeavours towards cures or interventions aimed at achieving ‘normalisation’. Advocates view neurodiversity like biodiversity within the plant world - something that should be an integral part of a techno-coloured world.

With ‘difference’ in mind, consider how anxiety, sensory overload and other characteristics can make some activities difficult, for example, hospital appointments or procedures. The invisible nature of AS - coupled with an affected individuals’ likely competence and compensations - often result in little external support, because problems aren’t - or rather the true nature of the problem - isn’t recognised. Many typical communications and interactions do not take account of the fact that the person with autism’s best way of communicating - and competency at communicating - may vary greatly depending on the environment and method used.

No accurate figures exist for the number of adults who are living with autism. While the generally held up prevalence figure remains 1 in 100, it is believed the condition is considerably more common than this.

Nowadays a significant number of individuals with autism will receive their diagnosis in childhood through a variety of routes including educational avenues, paediatric services or child and adolescent psychiatry. While there is no doubt that public and professional recognition of the autism spectrum has improved, there is still a significant number of individuals remaining undiagnosed or misdiagnosed. Many people who were presenting to professionals as anxious, depressed or with addictive behaviours are now being recognised as having strong autistic characteristics at the root of their challenges. It is common for these individuals to gain a diagnosis of autism with these other diagnoses viewed as co-morbidities.
An individual associated with the Aspergers group put forward the following:

‘Anxiety, depression, eating disorders, self-harm could be intuitively understood to be a result of seeking to navigate a world not well suited to their thinking/behaviour style. Many of these behaviours are understood to have control at their core and living in a world that one struggles to make sense of will lead people to grapple for control where possible. It will also drive the need to self-medicate as one seeks to salve the anxiety and depression experienced often as a result of confusion, fear and loneliness.’

Cameo

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 frighteningly 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 has the potential to significantly improve all aspects of her care, and consequently her life. On engaging even with a relatively small sample of the autism population versions of the above account are far from uncommon.

The age range for AS diagnosis is spread across the lifespan. Despite now being 5 years into the Autism Strategy diagnostic pathways for adults remain frequently ill-defined, difficult to access or even non-existent in many areas. There are considerable inequalities of care across Scotland.

‘It took far too long - 3 years - from my new psychiatrist believing there was a more appropriate diagnosis to [my receiving] an assessment. Until he suggested it as a diagnosis I would never even have considered I was autistic, as I had a similar views to many about kids who sat in corners and didn't communicate.’

‘I was very lucky. I did not have too long to wait and the interviews were conducted very sensitively and respectfully. [Edinburgh]’
'I'd managed to get by, was concerned that healthcare professionals may be quite dismissive of my need for diagnosis. I was very pleased I was taken seriously by my GP and referred straight away.'

If diagnosis is sought through a GP (or other health professional) the question arises as to whether they are sufficiently knowledgeable about the autism spectrum or whether 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 and other coping strategies (compensations) that will likely mask traits. This is now recognised as being a particular issue for women on the spectrum seeking a diagnosis - in fact until relatively recently they were all but being missed and dismissed completely. Will the front-line health professional with the power to refer look beyond the ‘labels’ an individual may have gathered such as hyperactive, highly anxious, anti-social, difficult or uncommunicative and recognise the potential root of such presentations as autism? Are such professionals willing to challenge their own personal preconceptions (prejudices even) when it comes to higher functioning autism - its ‘appearance’ and even its existence?

‘A new doctor noticed what was causing my problems. Without that I would still be lost.’

In the survey responses, feelings were equally divided as to whether contacts with health professionals were good or bad. 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.

‘Some people classed as medical professionals should not be allowed around ASD and depression. I have experienced OT and some nurses whose opinions and behaviour have been punitive and incendiary.’

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

This is particularly applicable when people have experienced compulsory procedures and treatment where they have felt completely overridden and disempowered in terms of their own lives and ‘care’. It is far from uncommon for some to have ended up with label(s), the connotations of which can be very alarming. On talking to those affected, such interventions have frequently had a far reaching, deep-seated psychological impact.
There are significant other barriers to be overcome by those seeking a diagnosis. Some of these are inherent to higher functioning forms of autism - largely in being understood!! These include differences in use of language and communication styles, idiosyncratic social development and variances in social and emotional understanding and perspective. Amongst other obstacles, this can lead to miscommunications in terms of what one person means and what another person understands them to mean. It has also been highlighted that there are issues around identity and the need for answers for one's life experiences.

‘...where people have felt a lack of explanation for, and faced considerable confusion regarding life, they may read/hear/research autism and unintentionally move underneath and into fitting the label for the want of explanation and a sense of identity …’

Despite autism being a neuro-developmental condition and not a mental illness, diagnostic services for adults commonly sit within mental health (or learning disability) services where treatment expectations are often focused on changing the behaviours and thought styles of the individual. As mentioned previously this is an area of considerable debate - questions arise, such as, is this an appropriate or acceptable way to treat people with autism? What does this approach do for their sense of self, their identity, feelings of validity as a person and ultimately their mental wellbeing? Will this focus ultimately 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.’

It is important that when pre-diagnostic, or full assessments are being carried out the person being assessed feels as comfortable as reasonably possible - and also that the environment they are in and the approach towards them is consistent. The attitude and approach of practitioners carrying out the diagnosis, and those whom one may come into contact with post diagnostically, can be vitally important in terms of the outcome of the process and how a person views the way forward.

As touched on previously members of the group reiterated that, for people who have lived their life feeling an ‘outsider’ the importance of belonging to the autism 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 seek an ethical and democratic autism
community which enables them to organise and communicate amongst themselves. This community can provide support, information and give a sense of positive regard. There will also be a number of individuals who will have no desire to access such supports and this should be appreciated too.

In terms of professional support, going forward, it is unkind and unprofessional to give someone a diagnosis of such a pervasive lifelong condition without provision of some level of aftercare.

‘There really MUST be follow-up support - I'm shattered trying to find bits and pieces of support.’

‘Felt optimistic at first. In North Scotland I'm very isolated. Late adult diagnosis desperately needs follow-up support.’

‘I feel that a diagnosis is the first step to building a healthier and more fulfilling life for yourself, however, without post-diagnosis support building a better life and addressing the aspects of your life that you have difficulty with can be so overwhelming that you can simply find yourself completely paralysed by the problems you are facing and can’t even start tackling them.’

‘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 nowhere to go to discuss confusions in daily life a lot of present services are a ‘do for’ service rather than ‘do with’ or enable.’

‘NHS psychiatrist terminated with me once diagnosed. "You’re not in the mental health sector anymore!!!’

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, domesticity, employment and relationships. Individuals will need gentle help and guidance to reach a degree of understanding of their autism - with the focus being on skills, abilities and positive qualities. These attributes often include, although are not limited to, a strong focus, tenacity, reliability, a low propensity to discriminatory behaviours towards others, loyalty and fairness, novel thinking styles and creative flair. Areas of difficulty e.g. social and
organisational skills should be remediated but this should not be at the detriment of focusing on strengths.

There is also a place for pointing individuals towards resources and materials that provide positive role models or figures of influence within the autism community. These are people who have capitalised on their strengths and/or who are succeeding in living fulfilling lives despite being known to have (or even for) their autistic minds.

Ultimately there needs to be continued improvements to the accessibility and consistency of the diagnostic process. At present pathways are still ill-defined and fragmented, with services that are available being considerably over-subscribed. More scope needs to be created for moving away from the deficit model and establishing a more beneficial model aimed at moving people with a diagnosis forward into a greater quality of life and societal acceptance.

Reflective questions
For the person with AS: Is it worth exploring afresh diagnostic support or services available in your area? Perhaps there are new facilities locally or online?

For the parent/carer: In what ways could you share your family experience of the route to diagnosis towards positive experiences for all?

For the professional:
• In the 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 autism feel included and listened to in an understanding and empathetic way?
Chapter 3  Mental Health and Wellbeing

Following on from the original version of An Ordinary Life, a number of contributors and other stakeholders highlighted the potential value of having a chapter which discusses issues around mental health.

This section therefore seeks to provide insight into experiences with mental health, as well as offering some practical suggestions as to what may help ease some of the challenges, and how associated thoughts, feelings and behaviour may be channelled.

Feeling “different” from others throughout childhood and adulthood - with a sense of isolation from society - frequently results in mental health difficulties, including anxiety and depression. In recent years therefore, an increased understanding and awareness of autism (and its not-so-stereotypical presentations) have led to greater recognition of the condition in affected individuals at the time of treatment or review of these mental health symptoms. Below one person states what is sadly not an unfamiliar theme:

‘I have always been prone to long and deep bouts of depression, fear and anxiety; self-doubt; self-loathing; deep feelings of worthlessness; and a strong sense that my life has been a failure. Many of these can be traced to neglect, bullying and mistreatment as a child, along with a feeling of having been excluded and ridiculed by my peers. Collectively this has led to isolation and in turn to intense feelings of loneliness and an inability to establish meaningful relationships.’

The establishment of, and confidence in, their own self-identity is often a fragile area for people on the spectrum. This is undoubtedly a reflection on their challenges with fitting in, and feeling adequately accepted, ‘validated’ and affirmed by others in the community - and perhaps even their own families.

A key contributor towards this publication, put forward the following:

‘I have been brutally frank with you about my hurtful past. It spurs me to persist in my quest to create dignified roles for stigmatised people. It is self-evident that everybody needs dignified roles as the sure foundations of self-respect and self-esteem. Those without dignified roles steadily spiral into co-morbid mental illnesses which may become untreatable if left to poison the victim’s personality’
Commonly as a result of this, and trying to meet the demands of life placed upon them, (more often than not, requiring to respond in ways which go against their distinct thought and processing style) AS individuals experience considerable anxiety and mood disturbances. A person can very much feel they cannot freely and safely be themselves - they are constantly having to act in a certain way to feel both accepted and to be acceptable. Their mental health is affected but it is highly likely physical health will be impacted too and more and more recognition is being given to the value of this holistic thinking and the complex nature of interaction between mind and body (known as psychosomatic relationship - ‘psycho’ mind, ‘somatic’ body).

‘The strong feelings of self-doubt that I feel makes it difficult for me to come to firm conclusions on most things and diagnosing my own health is just one of them. As a child I continually suffered from sore stomachs and associated pains, but the frequency of these made my mother decide that I was just making it up and she was therefore very dismissive of me anytime I complained. In the end I just stopped complaining and learned to put up with the pain it caused me.’

It is reasonable to suggest that inner tension, or stress, results in the need to find ways to calm oneself down and to feel able to cope in a situation. Socially and sensorily demanding situations are understood to provoke anxiety, however, less intense environments may not necessarily mean an absence of stress. Negative life experiences can often play over and over again in a person’s mind and since AS-affected individuals are particularly prone to repetitive (and often inward looking and analytical) thoughts. These can often be a substantial source of discomfort, or even torment.

‘I spend a lot of time thinking about my mental health and why so many things bother and upset me and cause me excessive levels of distress that most other people would not have.”

“A solitary existence makes life difficult and you can easily fall into the trap of obsessing about your own problems for inordinate lengths of time without there being any prospect of finding a realistic and/or workable solution.’

Approaches such as Cognitive Behavioural Therapy (CBT) are a useful tool for addressing unhelpful thought styles. These must be adapted however in a way that relates to the individual on the autism spectrum e.g. in relation to routine and habit or they can be ineffective, or even harmful. It is also essential that the CBT techniques are led by someone
who has a thorough understanding of autism. For example, typical approaches requiring the participant to imagine and reason from hypothetical situations, interactions and scenarios in the way neuro-typicals can readily do, can be very difficult for people on the autism spectrum and efforts can result in added stress and frustration. Fortunately these differences are being increasingly recognised in the clinical community.

To intensify challenges with some psychological therapies, AS individuals may find it extremely difficult, if not impossible, to identify their emotions - creating a problem in then relating how they feel. Many psychological interventions appear to require the ability to rate (on a scale) one’s own emotions. Significant difficulties in this area can stir up further distress and frustration as well as present obstacles in relation to monitoring, regulating and controlling one’s feelings and behaviour.

These emotional differences can generate or add to the incidences of “non-conformity” along with other variances in thinking style (i.e. the individual does not behave or respond in what would be regarded by the majority as within the boundaries of expectation or appropriateness). Unfavourable response by those around them (e.g. unexpected anger or laughter) can then lead to further anxiety and distress for the person with AS.

People can feel treated unjustly and as if there are considerable attempts to silence their voice. Many also struggle to make sense of the ‘wisdom’ of the world, including its advice and approaches to those with AS, as the following quote illustrates:

‘Ask ourselves why some messages are urged upon us eagerly by many books and others are not. To realise what is missing and not getting published, to read between the lines of books’ messages. For any wronged person, it is emotionally wearing to see how many self-help psychology books push, without even evidence, a message of helpless passivity, living in acceptance, “letting go”, and one-sided forgiveness. All making life even more permanently unjust for exactly the folks who have it unjust already, taking away hope of restitution. Contrary to common sense, it sells wellbeing as to be found in letting the society around you off the hook of caring or bothering to put problems right.’

‘We only have autism awareness at all because hurt people have made a fuss and have not been manipulated into pathetic acceptingness’ by cruel faux-psychology with a docility agenda

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behind it. But how often do you see these thoughts in print? We are left to work this out for ourselves, and not all do. Rarely do you come across a psychology book that asks why this forgiveness theory is often assumed without evidence, and itemises actual cases of further hurt felt from effectively being asked to say that what was done to you was okay.’

On a constructive note, it is helpful to try and channel feelings and emotions that are difficult to express verbally through other avenues. Although these outlets or expressions may not be interpretable by a third party, they can provide vital release from pent up frustration and overload. Choices may include - music (composing and/or playing), art (many and various forms from painting to pottery), writing (poetry, prose or song), crafting and other creative endeavours. Exercise is a popular choice as it has numerous health benefits (including being a known stress-reliever) by producing mood enhancing chemicals which promote a sense of wellbeing. One caution being however, that this can sometimes be taken to the extreme and become somewhat “obsessional”.

Other, more general coping strategies people stated include:

‘Distraction techniques and creativity, doing things I am good at or enjoy.’
‘Writing, volunteering, creative problem solving, visiting neighbours and being around animals especially cats, train travel, whisky tasting’
‘Limiting my time with people, only doing one hard task a day, having plans and contingency plans.’
‘Listen to music with earphones, read books.’

As understanding of the diversity of autism is increasing, the number of people with addiction issues or substance abuse problems being recognised as having related traits appears to be growing. Similarly, it is common for people on the spectrum to report battling addictive and self-medicating behaviours as they seek to deal with social environments and relational situations. These behaviours are not unrelated to the sense of loneliness, isolation, frustration and disconnection many people can feel as result of the condition. One person on the spectrum\(^2\) suggests:

‘Anecdotally, I can say that the people I know on the autism spectrum tend to use more drugs, and they use drugs to help them socialise. It does make sense - it’s much harder for them to socialise, so a “social lubricant” would be very helpful, but get to

\(^2\) http://www.bluelight.org/vb/threads/470621-Aspergers-and-substance-abuse
using that lubricant too much, and it can lead to problems. It’s easy to see where people could fall into that trap.’

High incidences of bullying, rejection and overall confusion can be experienced from an early age and this can leave people with a chronic sense of low self-esteem, reduced self-worth and vulnerability which can then act as trigger points for further pains in the future.

Alcohol, drugs and food can act as emotional painkillers which make memories and experiences tolerable - helping to dull and suppress discomfort and other negative emotions. Many know these behaviours are not healthy and likely lead to a downward spiral of destruction but are trapped in a cycle (admittedly like many non-autistic people) which they struggle to break free from and/or gain a sense of control over. Often when one addiction is overcome there will be transference to another behaviour which is, or has the potential to be, similarly destructive. Lynne Soraya, an author with AS, writes:

‘When I googled the terms “suicide” and “asperger’s”, I was surprised at how frequently the subject seemed to be treated with confusion - why would a person with Asperger’s feel driven to suicide? To me, the answer to this is obvious. The need to bond with others is a basic human need. The very definition of Asperger’s is to have trouble fulfilling that need. So why is it surprising that someone with these difficulties might fall into despair?’

Thoughts of suicide was an issue raised within the Ordinary Life editorial group. It became apparent that this topic was not alien to the group. An article within Psychcentral which discussed this subject cited suicide being 10 times more likely in adults with Asperger’s4. The piece referenced a study by Dr Sarah Cassidy, working within Professor Simon Baron Cohen’s Autism Research Centre in Cambridge, published in The Lancet Psychiatry5 in 2014, evidencing this.

‘Survey data was used on 256 men and 118 women who were diagnosed by a clinician with Asperger’s syndrome between 2004 and 2013 in England. Any depression, suicidal

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3 www.psychologytoday.com/blog/aspergers-diary/201011/the-pain-isolation-asperger-s-and-suicide
thoughts, or plans were recorded on a self-report questionnaire, along with self-reported autistic traits and empathy.

Two-thirds (66 percent) of the respondents reported suicidal thoughts, 35 percent reported plans or attempts at suicide, and 31 percent reported depression.

Compared with the general population, adults with Asperger’s syndrome were nearly 10 times more likely to report suicidal thoughts. They were also significantly more likely to have these thoughts than people with one, two, or more medical illnesses, or people with a psychotic illness.”

The author of the article quotes Professor Simon Baron Cohen, who co-authored the research, as acknowledging:

“Adults with Asperger’s syndrome often suffer with secondary depression due to social isolation, loneliness, social exclusion, lack of community services, underachievement, and unemployment.”

“This study should be a wake-up call for the urgent need for high quality services, to prevent the tragic waste of even a single life.”

“More detailed studies are needed into the triggers and experience of suicidal thoughts, the risk-promoting and protective factors for suicide plans and attempts in adults with Asperger’s syndrome (such as age at diagnosis), and family history of suicide and aggression…”

The AS author of a piece in a previous publication⁶ reflected on the findings of a research study into the increased occurrence of suicidal thoughts and ideas in children. She states:

“They [the researchers⁷] also found that a history of bullying was also very much associated with thoughts of suicide. What’s interesting about this group of findings is that they suggest that the chances for suicidal ideation are less related to the neurological differences related

⁶ www.psychologytoday.com/blog/aspergers-diary/201303/new-research-autism-and-suicide
to having autism, but more related to social factors....in other words, how we are treated as a result of those differences. This is an important distinction - one that’s missed by many”.

This last quote drives home the importance, and potential impact, people’s attitude and approach to those who are different can make. It gives a glimpse of the potential impact raising awareness with the goal of promoting increased understanding, inclusion and acceptance, could have. It may not happen overnight but with persistence in encouraging greater acceptance, society and, in turn, life, can improve for those with autism.

Reflective questions:

• In what ways, if any, has this chapter on mental health enabled you to think differently about the lives of those you live and work with who are on the autism spectrum?

• Within your sphere of influence - even on a relatively minor scale - what could you do that might impact the quality of life for those with autism or Asperger’s? e.g. offering help or assistance in some way, friendship, acknowledgement.
Chapter 4  Relationships and Family Life

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. However, there is often a strong desire to have the same range of relationships that the so-called typical person enjoys. Across the life span the number and type of relationships tends to grow. The function of relationships change and we become increasingly aware of the shared responsibility we have to make family, friendships and intimate relationships work.

‘I have very few relationships with people that go beyond a very superficial level. I have struggled to develop and maintain friendships with people and there are very few people in my life that I could honestly refer to as a “friend” in any meaningful sense of the word. This is very problematic for me as I want to have relationships that are deeper than this and that provide me with a social network I can be part of.’

As one example of how relationships evolve, consider the change in dynamics from the wholly dependent newborn 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 lack of regard for other person’s feelings, beliefs, desires or needs. By talking to and engaging with people with AS, it is clear that lack of understanding is not an equivalent of not “caring” about people but rather a lack of 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.

‘To other people and from what I understand, many have misunderstood my intentions and my language particularly in formal situations as I take things very seriously. I need to know people for quite some time before this misunderstanding eases a little.’
Personal and Professional Perspectives

Some people with AS may not admit openly that they desire friendships and relationships. They may not even admit it to themselves as it perhaps too painful. It may be easier to deal with if they just believe that they do not want to socialise rather than admit that they are not able to form and maintain relationships. The celebrity culture that is evident in today’s society often results in people feeling and believing that the more popular you are, the more worthwhile you are. To admit openly that one has no or few friends may add enhanced feelings of worthlessness. There may be a concerted effort and tendency to channel one’s energies into what they feel relatively successful at and gain positive feedback from that rather than that social relationships which may repeatedly lead to emotional or physical setback.

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. Many may even assume people in the autistic spectrum are incapable of doing so. This may be the case if the 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 who have AS.

“The simple fact is that 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 be often challenging for a person on the autistic spectrum 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 variations of AS will one day impact on them.

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

The 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 a characteristic 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 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 in family dynamics and to take care not to make assumptions. People on the spectrum are sensitive to this and articulate their experiences and views on this in a variety of different 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 with AS - namely their difficulty in “factoring in” other people’s perspectives and requirements and even if these made known to them then they can lack the mental flexibility to accommodate them.

‘My parents died before I was diagnosed. I can think of many family rows over monumental trivialities and rows with my brother. Looking back I recall rows with my father about religion, my hobbies, Christmas presents, hillwalking, my choice of clothes and ludicrous remarks he made’.

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 generally 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 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 can 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.

‘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 stress that despite appearances the AS member(s) may just be being selfish and blatantly disregarding the needs of others although it can very often look 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 shun the idea that people with AS are incapable of selfishness, far from it, but it is important to bear in mind that actions and behaviour are far more 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 to 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 with AS will require to be told what is expected of them in their role. This is likely to be because they do not naturally or instinctively know what is expected in a given scenario and what it would mean emotionally to others involved. This lack of knowledge and fundamental 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 his partner 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 almost 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 a "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 anti-social, merely that they are 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 fleeting 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 more intense and interested than them, so it 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 with AS make 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 imitate level. Males can be afraid of coming cross 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 can too 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 or 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 over time and put into practice. So it 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 being a father, and said “no”.’

The mutual nature of trust is important. One individual describes the expectations 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 autism spectrum disorder. It therefore seems inevitable that professionals will encounter people who are on the autistic 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 kids have appointments, not their school, nowhere.’

This is likely to be due to the fact it has only been relatively recently that 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 of 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 the study. Participants were a mix of formally and self-diagnosed individuals. 6 participants were female. Parenting experiences accounted for one area explored in the study. She asserts that AS is not an indicator of poor parenting just as those who are typically developing are not routinely/automatically 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 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 the 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 have 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 typical 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 preconceived ideas that influence your thinking about this?
Chapter 5 Education and Training

Cameo 1

*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 aged 4 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

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and cater innovatively 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\(^\text{11}\), 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 wellbeing.

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. It 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 they are taught in can often be inaccessible.

There may be 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 “common sense” 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, PE 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.

Indeed, many people who are on the spectrum have the intelligence and academic ability to make it to university and get a degree. But this is often a challenge due to the transition from secondary school to higher education at a crucial transitional age. Students going up to university have to deal with more changes in their lives than ever before, including leaving the family nest to move home and live independently, meeting a whole new circle of people, and becoming accustomed to more self-directed study rather than following a structured curriculum. For some with autism, this level of intense change can be too much.
“At university my expectations were too high; I had it drummed into me throughout the misery of school that at university I would meet people like me and fit in. Of course I didn’t as I was so isolated and not encouraged to develop social skills. I tried too hard, or I was rude and introspective and dumped my problems on people. I went from being a bullied child to an adult who should have known better and deserved everything bad that happened.”

University becomes an education not just in the academic sense, but also in terms of independent and communal living. Flat shares are the norm for most students, for example. It is much more of a social education compared to what one learned from the school playground. These are the exact sorts of things that present the greatest need for support for the person with autism, at such a transitional time.

Getting outcomes heard
Parental anxieties create a big market in advice books about coping with school, and psychologies of children’s needs. Trust in such books may be affected by knowing what it is like on the writer’s side, trying to get something heard that is outside publishers’ comfort zone:

‘It is a problem dealing with business, when an aspie who has survived a terrifying trauma of school pressure supposed to be unable to happen can not make its causes widely known, not even by pointing out to publishers that all children’s safety is breached unless they take it on. The horror of having your ability level decided for you, and too highly, by severe and pushy teachers, never features in education policy debate and research, and media coverage. In the absence of any already existing powerful body of feeling against letting children get caught in breaking point situations, publishers have no fear of ignoring it, no expectation that a liability for letting these things continue could ever be chased up, and no perception of a market wanting to hear it. Yet that makes a vicious circle that continues all hidden ill-treatments perpetually. They can also find it an easier business practice to just automatically consider such writings a defamation risk, without looking at how well evidenced it is or using false name’.

‘I wrote recorded to 20 publishers, about our writing here, asking them about this. The key question, asked “for an audience with work responsibilities affected by it”, was - “Do you acknowledge to our Forum’s followers and members, that evidence of any forms of child harm that are not already widely appreciated in media and politics has an absolutely fixed humanitarian automatic right to be published? To say no, either by saying no or by ignoring
the question, would show willingness to endanger children.’ (Even post-Savile, none at all answered it).

“There is no greater agony than bearing an untold story inside you’ - wrote US black civil rights figure Maya Angelou. Pooled experiences make the difference being forewarned of troubles, and we can't rely on the media for it. It has been a convenient myth that the internet is a new place of free publishing, when ultimately the domain hosting companies for websites have physical control over what is online, and they always reserve a catch-all discretionary power to delete online books, without having to look at how well an assertion has been evidenced.

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 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 6 Transitions Into Adult Life

Introduction
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.

Autism is a neuro-developmental condition - this means it takes longer - emotionally speaking, to be ready for the next step in life. For many people on the spectrum, when they think about 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 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.

‘I can provide vivid and poignant reminiscences of my transition to adult life such as an unaccompanied stay in Dieppe after leaving school but paramountly an event when I had taught myself German in the dormitory at boarding school before lights out and what happened later in Cologne then sadder things that happened when I became unemployed.’

Not having enough skills makes failure more likely. Repeat this a 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.

For many on the spectrum secondary school is a very testing time. You are 11/12 year old who has just arrived from primary school which itself has its own issues but the lessons were taught in a child-like manner which aims appears to be mixing education with fun and play, in all being with the same group of people (class). Secondary school, however, throws children into a more serious environment and new unfamiliar patterns emerge. You are naturally split from the class you were used to being with and this group of people also shift and change within a new timetable and demands that you take lessons that are drastically shorter than before and all with different teachers. This environment also demands that you start thinking about your work ambitions and offers work experience and on top of that you are taught sex education through science and social education plus learning a new language (which appears compulsory), a heavy load for any child to take on, far more for one with an autism diagnosis.
'The transition from childhood to adulthood during the teenage/puberty year was terrifying. I was used to being a young boy with an over-active imagination and I did not want to change. The pressures of secondary school threw heavy burdens like “career planning” and “sex education” which effectively ended childhood innocence abruptly. This along with involuntary body changes due to puberty took its toll mentally and emotionally. In simple terms I was a child who fought hard against the “natural” transition into an adult and it broke me down.'

In later secondary school year comes the pressure of sitting written exams and the fear of not passing them meaning impending doom for adulthood. The impending pressure of the expectation that the child becomes adult at the age of 16 and MUST be ready if you are to succeed. Schooling, primary and secondary, despite its pressures, becomes a safe haven and the transition into further education (university/college) or employment (including apprenticeships) is a very big fear and there appears to be no proper preparation for this.

The careers advice service, for many on the spectrum at their individual time of transition, did not aid them when it felt it was needed. Some felt it was too formal and rushed while others just did not feel “ready”.

‘The transition into adulthood was more traumatic than I ever imagined it could be, and time and time again I failed to achieve the things that I saw all of my peers achieving because I lacked the social skills that they had. I had no idea how to develop relationships and lacked the support networks that can stop you from being overwhelmed by day to day living and spent much of my time bewildered by why I couldn’t achieve all those things that came so naturally to everyone else. It distresses me just to think about the misery caused by my social isolation at this time, and it is definitely not a period of my life that I would like to relive.’

It is not just the educational and occupational sense that many autistic people find tough to contemplate without a sense of dread. Moving on from home is one and with that the fear of self-responsibility which includes money management and living skills. Then there is a responsibility of dealing with food shopping, dealing with the bank, dealing with local authority/housing association/landlord, management of different kinds of expenses such as rent, electricity and gas. The list is endless and a lot to comprehend as well as losing the comfort of familiarity.
“I felt lonely, frightened, at sea, didn’t want to be doing what I was doing, my friends were all going off elsewhere, I was in a strange city, in a horrible flat with horrible people, couldn’t stick to any of my routines that helped me cope, didn’t have my dog, didn’t know where to walk. I had no signposting or idea of where I was going.”

It’s not that people on the spectrum cannot change and develop. It is about the stress of society which enforces change at certain stages in life and it’s hard to prepare for this. 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 meaning reducing the extent to which it will feel alien. Visit the buildings or premises if applicable to familiarise yourself with it beforehand and meeting the relevant individuals the situation may involve.

If the transition in question is a life stage, it may be helpful for 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. 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 on 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 7 Autism and Employment/Employability

Introduction
When we discuss employment, we need to be conscious of the terminology we are using. Words 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.

‘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.’

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.’

‘On one side of the coin, challenges wise, I have often had serious difficulty in the actual securing of employment. Getting interviews was always no problem, especially due to the sort of CV I built up once I eventually gained the jobs that I've had. It's getting through the process of the interviews that was a great problem at times. So much so that there are two different periods in which I only secured a job following 25+ interviews each time. I have no reason to believe that this is not a bit extreme.’

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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, is counterproductive and in the long term a more staged approach is better.

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. Recently, the Universal Credit has been introduced across Scotland and the rest of the UK, and the gradual introduction of this system is complicating matters further.

The experience of people with autism is that the benefits system 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.

From April 2017 Scotland will take over the responsibility for the UK wide DWP Work Programme. The existing contractors will be commissioned to deliver the service for only one year. From 2018 the Scottish Government will launch a new employability programme. We must wait to see if a more individual approach is adopted which will be more accessible to people 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.

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. Whist 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.

‘It is fair to say that Asperger’s has contributed towards employment difficulties for me, especially when it was undiagnosed and therefore I didn’t grasp why I was running into so many pitfalls in my work. The first job I got, straight after graduation, didn’t exactly help matters either. It was in a company which could loosely be described as a recruitment agency. It was involved in “selection by personality”, using psychometric testing to help companies select candidates. Because this was a ‘one man band’ company where it was just me and the Director, and was only just in start-up stage, it did not have any sort of proper company structure. So the Director felt very much able to run things disrespecting standard working regulations. As a result I was forced under duress to work at least 12 hours every day, in order to help grow the company in this immediate start-up stage, and because of the Director’s pathological need for immediate results and lust for money.’
One of the ways you can get support in the workplace is the Access to Work programme administered by the Department of Work and Pensions. It’s only available at the moment once you are in work or when you get a new job, start a business or become self-employed.

Historically people only used Access to Work to buy specialist equipment or pay taxi fares. In reality it can also pay for:

- A Job Coach to help in the workplace
- Disability training for co-workers
- Communication support at a job interview
- The cost of moving equipment if changing job or moving to another location.
- The maximum an individual can have in any one year is £40,800.

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: panels etc. are likely to be helpful for all candidates 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 and interview location need to be detailed for the autistic candidate.

- Disclosure - it is a very important and difficult decision whether the person with autism should disclose their condition to their employer and to their work colleagues. It is difficult to know sometimes what the consequences of disclosure would be, as this depends on others’ prior knowledge and experience of autism.

‘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...'
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 this is demonstrated.

- **Occupational activity**

  Volunteering: This can be an important part of the development of an individual’s confidence and work skills.

  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 interests 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 but that same activity can be structured to have real
learning opportunities that link to the development of the person's 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.

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 be seen as one where everyone would necessarily progress in the same way 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.

*I managed to hold down jobs continuously for about 28 years and feel as though I learned a lot about social interaction in general which I would never have had the experience of had I not worked. I think it’s sad that many people with Asperger’s don’t have jobs as it is this constant practice and re-adjustment of dealings with others which can help people adapt and fit in better. The workplace is a great place to learn social skills. It is a great thing if a person with an ASC can find a job in amongst understanding colleagues although this isn’t very common. There just aren’t many jobs about just now.*

*The social side of work such as coping with tea breaks, lunch breaks etc. can often be the most nerve-wracking part and it can also be how a person copes with this which determines whether or not they keep the job. In most workplaces it isn’t how well you can do your job, but rather how well you fit in with your colleagues which can make or break the job.*

**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

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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\textsuperscript{14} (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 you 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?


\textsuperscript{14} Grandin, T (1996). \textit{Thinking in Pictures}. New York: Doubleday
Chapter 8 Leisure and Wellbeing

Maintaining one’s health and wellbeing is as important where those with Asperger’s are concerned, as it is with the mainstream population. This chapter discusses the value of leisure time and activities in relation to a person on the autism spectrum. In addition, it touches on other aspects of living and daily life which combine to enhance, or erode, overall wellbeing. Mental Health is covered more extensively in Chapter 3.

One of the most important things in life for people with Asperger’s Syndrome can be a regular amount of time each day to carry out leisure and recreational activities. Music, art, crafts, drama, sport, a quiet time on the internet or in the open countryside are examples of pastimes and pursuits which can provide considerable enjoyment and relaxation. Having Asperger’s will often mean that the individual will feel overwhelmed by daily life and its undertakings at a lower threshold than non-affected people.

‘everyday activities for me are physically and mentally exhausting which limits what I can do.’

Scheduling activities in which they can recharge and recoup is therefore vital for maintaining and restoring health and wellbeing.

‘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.’

‘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.’

Whereas many non-autistic people will ‘chill-out’ by being with, or around, others and chatting through their day, for example hanging out with friends in the pub, those with autism will more often require more solitary pursuits. The influence of social situations therefore often has a converse effect on energy levels than they have on many neurotypical people.
'I enjoy walking in hills as it is very quiet there and no-one else is generally around. Going to the country - where there is vast space - is wonderful.'

A large proportion of people on the autism spectrum can relate to indulging (often involuntarily) in considerable ‘overthinking’ - introspection and rumination. This can be a real hindrance in terms of maintaining one's peace of mind, inner calm and general wellbeing. Spending time doing things one enjoys provides a degree of escapism from one's own thoughts and enables you to get lost in that activity for a time - a kind of getting away from, or out of, yourself.

'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 off 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. '

'....activities also give basis for conversation which aids social inclusion for one who finds this difficult. Confidence can grow as a result.'

There is also another aspect to life on the spectrum which can be typically Aspie. Some individuals have ‘occupations’ which may appear recreational to an extent, but are more related to the need for sameness, routine, structure, order or having things ‘just so’ than they are leisure pursuits per se. In this sense, these undertakings could be said to play a part in maintaining wellbeing as long as they do not spiral out of control and encroach too much on one’s life; with the need to do them becoming a strong source of anxiety or preoccupation.

'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.'

Collecting items or information about a certain topic is a common hobby of people on the autism spectrum and one in which they find considerable fulfilment and sense of satisfaction.
'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 or interest and this can be a really beneficial step. People with a strong interest in a common topic are often much easier to chat to and this can serve as a bridge to feel a sense of connection and mutuality with others. When associating with others in this way, there is not the same pressure to be ‘au fait’ with the latest TV shows, films, popular interests etc. Indeed due to the nature of particular interests, there are a number of hobby and leisure clubs which are more likely to attract people who are on the spectrum, or not far off it, and therefore there may be increased possibility of meeting others who are on the same, or a similar, wavelength.

‘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’

Sadly this is not the case for everyone however:

‘It must be good to have friends and relationships with people who share your interests and passions. Despite the fact that I have spent most of my life going to concerts on my own and still thoroughly enjoyed them, I can’t help but think that there must be great satisfaction in having a shared musical experience with another person who is also interested in performance. Again it all comes down to social skills and the ability to build and develop relationships with people, although in this case it would specifically be through shared common interests. Depressingly, I find it very difficult to imagine a time when that would happen for me, but still hope that it does.’

Finding an environment that is welcoming and conducive to autistic sensory perceptual issues is also highly important:
'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.'

Conversely one contributor said:

'I love going to the gym, but round here they all have very noisy music playing constantly and big screens with the news constantly showing on them which are hard to avoid, I can't cope with the news and the noise is overwhelming, similarly our sport centre swimming pool is used for school lessons every day, with lots of kids and local radio blasting out, they have some lanes for public swimming but again noise too horrendous to cope with.'

Often people on the spectrum feel a sense of embarrassment or even shame, about their favourite hobby(ies) as they may be considerably different or more intense relative to what 'NT's' would pursue. This can lead to mocking and ridicule especially in the younger years when there is often more of a sense of pressure to conform to social norms. It is seldom seen as 'cool' to be into collecting stamps or studying everything there is to be known about horses when you have no interest in caring for them or riding them.

'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 by 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.'

It can be a challenge to fit sufficient leisure time into one's day, especially if a person has a family or other substantial responsibilities in life. A valuable skill to work on is developing good self-assertiveness skills which can be implemented when people try to intrude to such an extent that an individual is likely to feel overloaded to the detriment of their health and wellbeing. This is a commonly reported issue for many within the general population, but for people requiring significant down-time it is even more relevant. It is something people coming into contact with people on the spectrum should be alert to, especially as, unfortunately, some may find it a challenge to notice when overload is occurring within themselves, which can lead to insidiously escalating stress and depression without adequate awareness of why.
'I limit how much time I spend with people and try to ensure time 'off'; I have a dog and walk in the fresh air; I spend time in the countryside looking at trees and sky and listening to the sound of running water; I limit how much time I listen to the news; I watch very little TV; I try to spend time on a regular basis with people I like and who make me feel ok. I cuddle my children (when they let me these days...)' 

If stress and depression are a feature of a person's life it may be an idea to consider and explore options in terms of taking up a new hobby or interest that could perhaps alleviate some of the symptoms or their intensity.

'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 to the benefit of others, instead of my rather pointless solitary existence at the moment.'

Mental health related issues impact significantly and with high incidence on the lives of those on the spectrum. Many are challenged by depression and anxiety as a result of finding it difficult to conform to the expected pattern of the world and to feel valued, integrated and connected. This has considerable implications for motivation and healthy lifestyle patterns.

Lack of knowledge relating to diet and exercise may play a role but unfortunately it seems more likely poor lifestyles could be seen to be the result of a lack of motivation and apathy to exercise and psychological support to ‘spur one on’ to such activities. Poor eating habits are arguably for reasons that are more emotive and psychological than physiological or down to a lack of education around healthy lifestyles.

'When you lack routine and structure in your day or lack the security of established relationships you can end up eating more than you should, and often falling into patterns of low activity.'

This area is perhaps one for consideration is terms of targeting, encouragement and goal setting by a third party as it is often relevant to improving overall health and wellbeing and one that can be challenging to self-administer.
‘A great part of health and wellbeing is therapeutic activity, something that can both distract you from negativity and boost positivity in your life. In my experience playing sports is one way to boost wellbeing and of course health mentally and physically.’

‘Football is a simple game and one that can be used as a positive distraction technique in which its members can forget their problems for a while and sometimes use as a stepping stone in their recovery from illness.’

In contrast with the above, some Aspies can become almost obsessional with healthy living, diet and exercise related matters. These can become their ‘special interest’ and it is easy to see how control issues can very much come into play, especially given the influence of the media on weight and appearance and the sense of validation and worth it erroneously claims to bestow.

Eliminating or reducing dietary constituents such as gluten, wheat or dairy has been found by some people to have a profound impact on their well-being. Although this has not been scientifically verified, it has been acknowledged anecdotally time and time again that alterations in diet improve negative symptoms of autism as well as addressing gut related sensitivities.

Dental hygiene can also be a challenging area for autistic people. The invasive nature of dental work, required close interpersonal contact with the dental practitioner, and associated sensory sensitivities is often thoroughly overwhelming. It is important that health care practitioners are informed about autism so that the necessary accommodations can be put in place and understanding increased to make dental check-ups and required work more accessible and tolerable. Negative childhood experiences of the dentist feature highly in many people’s accounts of early life and this does not bode well for future engagement. Many no longer go to the dentist.

Attending hospital, doctors or other appointments of a medical nature can be very stress inducing and bewildering for a person on the spectrum. There can be a number of concerns around expectations, sensory issues and differences in communicating and understanding which can lead to confusion, misunderstandings and distress. It is suggested that appointments are missed and symptoms which warrant investigation go unattended to because it is too much of an ordeal for Aspies to attend the relevant service. SWAN\textsuperscript{15} have compiled two fliers which seek

\textsuperscript{15} Scottish Women's Autism Network - http://www.autismnetworkscotland.org.uk/swan/
to provide pointers for Asperger people (women in particular) when it comes to dealing with clinicians and clinicians dealing with Asperger people. These are accessible via the link referenced below. Given the relational nature of the condition, having somebody to accompany you to appointments who may be able to provide reassurance and support to appointments can be an additional barrier to affectively assessing services.

Visiting the hairdresser or beauty salons can be a real trial with many - particularly Aspies males - opting to cut their own hair, or let it grow considerably, rather than endure the sensory and social assaults of a salon or barber. This can be a solution in part, but can open the way to further obstacles in terms of social blending and acceptance, particularly if the resulting look is conspicuous.

Again this is an area which could be further investigated in terms of widening access through increasing education, awareness and understanding amongst those in this business.

In summary, it is apparent that aiming to maximise wellbeing and leisure opportunities for those on the spectrum is a complex one. Nonetheless, it is very much an area that needs to be addressed if we desire to enhance the life experience for those with Asperger's and benefit those around them.

**Reflective Questions**

*For the person with AS:* Thinking about anything discussed here, is there anyway your leisure time or general health could be improved upon?

*For the parents/carer:* Are there any ways - even small changes - that could improve the quality of life for the person in your life with autism in terms of leisure and wellbeing e.g. suggesting walks, attending a group with them.

*For the professional:* Does any of the above provoke thoughts/ideas as to how the lives of those you come into contact with on the spectrum may be improved? If yes, in what way?
Chapter 9 Community Access and Inclusion

Introduction
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 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.’

‘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”.

Our community
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.
'Not knowing how to start a conversation; being unsure of what is appropriate to say; fearing reactions;'

'People are very judgmental and first impressions can stick, autistic people who do not look or act like their mainstream counterparts are easy targets for those who seek social status through putting others down, criticising them and creating cliques' (see also p 88).

'Sensory overload is often not understood. Our social difficulties are mistaken for deliberate awkwardness.'

'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.'

Rejection is prominently there as a trauma, an un-valuedness of your wellbeing, a destructive act in society. It goes to the core of inclusion and physical health impacts of unchosen isolation. Yet the boundaries of service of the autism One Stop Shops has always been known to cause these feelings for spectrumites living outside the line.

Much division and upset has been heard in the Central Belt Aspie scene, of the hurt of those living slightly outside the council boundary of the city of Glasgow, which just runs arbitrarily through continuous residential terrain on nearly all its sides, with only those inside the line served by the “ARC” One Stop Shop. Arts and crafts at Edinburgh’s “Number 6” every week for 10 years excluded an aspie particularly known to be keen on them. His skilled contribution was lost, because he lived a few miles outside its boundary, a lot closer to it than some places within its boundary.

That they have boundaries and close their doors to those living outside them, instead of open door drop-ins to all autistic folks who can reach them, is a choice in the system’s design. It has lasted for 11 years now despite the feelings of already much life-hurt autistics, and complaint in the served population too that the division ruins meaningful quality of the service’s social side. Of course the One Stop Shops are about access to the autism community rather than neighbourhood community: ease of use will always be affected by travelling distance to them.
The experience of the Asperger Forum members suggests that part of the answer lies in being included and integrated with one's own community. Our Asperger forum serves inclusion in the serious business of influencing the direction of autism work: it is a gateway to raise to the professional community the topical issues concerning us. At the personal level, our meetings and local autism societies and online communities with meet-ups, all have served a wish to be with like-minded others who you can share experiences with. This serves for feeling part of a community, the community around our condition where we share the experience and understand each other's challenges and feelings.

For these benefits we need there to be a strong grassroots autism community accessible to us. It matters to keep our scene as an including national community for us all. It goes beyond what all of our local communities can give us.

'One of the group, not feeling odd or thinking you are.'
'People need social milieux where they feel valued and comfortable where they can excel in their own right ways.'
'Sometimes there is exclusion from within the autistic community: people who are constantly offended and correcting everything'.

There are not yet local Asperger societies everywhere, for the adult sector over 16 that is not covered by parent and family societies. So societies have a responsibility to less locally located folks. Even if there is a group we can reach, is the nearest to us a rightly organised type of group? It is important to suss that out, ensure that it is a tolerant autism community that works properly, where everyone can communicate, participants can write as well as talk and everyone makes an effort. Is it a democratic group with a code of practice on preventing rejection experiences? Or is it a sheeplike group so run by one strong leader that he/she can just proclaim to you "That's not what (name of group) is about" when you propose a letter writing in support of a member hurt by a particular experience?

Such groups can link to leisure opportunities. Some feel more at ease in the intimacy of smaller groups, some in the wider spread of contacts and friend opportunities when a group grows bigger. A big group could then have smaller offshoot subgroups for those who need them. Here is a conflict between 2 autistic folks' views on their inclusion needs:

'What you said about having a limit to quantity of friends, even though you know you will risk doing hurt by it, is exactly the type of attitude that convinces me there is no safe way to
rebuild any NT-type social confidence without the risk of getting hurt. I need not to face invisible personal limits like that, before I can ever feel safe to go first in making any social move. I must never base social life or hope of it on spontaneous proposing of activities to friends. I have never been able to make that work. If the only way to find out I am on those terms with anyone is to try it out, it carries too much risk of backfiring.

This means I need to belong to groups/associations with regular meeting up cycles. A shared interest activity is a way to get personal contacts without anyone having to suggest it, get timings right, etc. But in order to have access to opportunities to make any ties like this, I have to live where it is likely to be found, in the denser populated regions.'

Bar barriers
It generally feels daunting to go into an unfamiliar pub except with pre-existing friends. Even then, the bigger town centre family dining bars feel more welcoming. These have been social spaces for autistic groups and meet-ups to use.

Their emergence, a quite recent social change, has been a gain, for the provision to young people, who the whole social space that is bars used to be hurtfully closed to, and in providing an indoor tabled social space where groups of friends can sit for several hours entirely anonymously to the other people around them who are doing the same. No longer an expectation to connect with, get on with, be approved by, the other people in the bar all as one community.

Any intimate local pub feels loaded with un-predictabilities, as to how it will feel and how its well established users will react. So, though such a pub helps to bond a community that already exists, it is no route out of exclusion for the socially anxious. Even worse is when pubs have unfriendly signs on reserving right of admission - nobody but the narcissistically confident or friends of the proprietors goes into a place like that. Or signs about local football colours and restrictions. A local can hit too close to home, literally, as part of the difficult rowdier side of local NT life, not adapted at all to cushion more sensitive lives.

Shopping
We found a feeling that shops and traders need to adopt a customer focus which has been lost over the years as shops have got bigger. Yet some find the anonymity in supermarkets helpful
too. “its nice to be nice”. Environments need to be more autism aware and this would help other groups, neurotypical people seem to like autism style environments too.

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.

‘Online I can take my time and don’t have to interact with people or be pressurised as a queue builds behind me’

‘Groceries I shop in person as I can properly evaluate what I want’

‘I have always loved shops and would hate to see them gone with all having to be done online’.

‘Buying comfortable shoes that will last means going into the city. If successful then I don’t have to repeat the experience very often. Recently I was lucky to find a good pair of shoes in a sale and completed my transaction quickly as the shop was not busy. When I got home an opened the box the shoes inside were two different sizes: this meant returning at a much busier time to try to exchange the shoes. I had to explain the problem to an assistant, then to the manager and then they couldn’t provide a replacement so I was asked to complete a form to have a refund. This would be difficult for anyone, for me it was stress and high anxiety and I had to leave the store saying I would return. I couldn’t. As a result I still have two odd shoes.’

In villages and smaller towns local facilities have tended to disappear, and become distributed more thinly serving populations over a region, with more need to travel to reach them. As small local shops have declined as a sector, in many rural areas shops are ever more distantly spaced and banks and libraries only exist in travelling vans whose timetables can need juggling with work hours. In big urban settlements the culture is to expect facilities within local reach, but how easy are they to find, are they concentrated together or located randomly? Is a place community spirited enough to find ways to replace disappearing facilities, or to sustain a demand to keep them within local reach?

‘My local Tesco gave no local reason, only national policy shift, for removing a copier which had been a popular small town facility ever since it opened. “There are occasions when we need to make these types of choices” is patently not an explanation. In some communities, including there, local libraries have realised the need and provided photocopying, the public
sector reinstating a social service abandoned by the private sector. But libraries’ budgets are squeezed…”

Whose community?
At least dealing with an organisation like Autism Network Scotland (ANS), or any serious issue-minded autism society, we know we are among folks who share our cares about problems and getting them solved. By contrast you never know that when dealing with a problem in your local community, with its mixture of motivated and apathetic, caring and uncaring, and everyone having very different interests. There is not usually any outlet for us to share local concerns. Even when there is a community council, how many ears does its business reach? Feelings of powerlessness often follow for the affected folks when councils and businesses axe services, as they can do that feeling more confident of not suffering much consequence.

Feelings that you can make no difference to your state of local life are linked to council unresponsiveness or non-commitment to problems with council supported projects that behave in corrupt or socially cruel ways. It is devastating, and despairing to an depth risking suicidality, to be completely helpless and unhelped to stop a project that has maltreated or rejected you, from continuing to portray itself as doing good and be believed. It is the same feeling as when a big autism charity chooses to ignore an issue that matters to us and we still can’t stop local politicians liking to be seen cosying up to it. An outlet, a hearing, a place to expose these things without always getting slapped down that it is unrespectable, not positive for public relations, or might be defamatory, is key to whether marginalised people’s efforts to find inclusion can or can not end just in hidden emotional abuse.

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 locally, through school etc, 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’

‘Good practice by a local library: female staff upheld me a male aspie against the gender prejudice that men should apologise for existing. A mother and adult daughter had sat on either side of me, conversed loudly over my head and rocked a baby’s pram in the edge of my vision, then accused me of staring for reacting to the distraction. They got told this was clearly unreasonable’.

Whilst such barriers are acknowledged, finding answers to social inclusion is more difficult. Communities change and it’s 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 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’.

‘Cannot work out which people I can “come out” to outwith our small ASD community’.

‘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.

‘People with an ASD aren’t all white middle class males with just the 1 disability. All forms of oppression are linked, it doesn’t make sense just to focus on being inclusive of autistics, your whole environment has to be geared towards trying to be inclusive for everyone’.

‘A few suggestions for being inclusive: British Sign Language sign for clapping (jazz hands) rather than clapping; detailed agendas in advance - some autistics will have other disabilities too, e.g it’s important to offer materials in large print; quiet rooms (many people benefit from this); dispersing into multiple rooms rather than having 1 room with many people chatting’.

‘You can’t impose inclusivity without being enthusiastic about it, since inclusivity of an environment emanates from an inclusive spirit. "We don’t do X because no one with Y comes here”. How can you be sure? Perhaps they don’t come because you don’t do X?’

Further suggestions to support community inclusion follow:

- More communication and better public awareness, of the positives as well as the negatives. More sympathetic reporting in the press would be a start.
- Better information and training. More options for contact, like email. More safe neutral ground where people can meet.
- 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 its 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 proportionally represented on the ASD Governance Group: representatives should be elected by their peers. 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, e.g. awareness raising?
• How can self-representation be facilitated?
Chapter 10  Housing and Accommodation

This chapter considers supported accommodation, residential facilities, own tenancy, social housing and associated 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’.

‘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 hypo-sensitive 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’.

Neighbours
‘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 struggling with the impact of neighbours 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 chapter 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’.

Owning
Not all people wish to rent permanently, and there are some individuals on the spectrum who, like many other people, see home ownership as desirable. While it is certainly not something anyone should be coerced into, many aim for owner occupation for its independence and its long term security compared to renting. However this can cause challenges and consequences for people with autism when dealing with the property industry, so this should be weighed up against the desire to own a home. It is a lifelong commitment and so can bring severe pressure and stress.

Neither an autistic person nor a supporting worker should accept as settling any question someone’s claim to be acting on legal advice - because how do you know the advice will not be reversed abruptly under their feet, and the solicitor who gave it even hold them responsible never to have taken it in the first place!!
Case C/02/650/FS/ht in 2003 (and who knows how many earlier cases?) on a house sale for an autistic client, established that the regulator for solicitors, called the Law Society, considers them entitled to change their advice after causing a client a large loss, and to hold the client responsible for believing the advice that caused the loss:

‘A problem with planning certificates for building work by the house’s previous owner had not been solved by the (different) solicitor at time of buying. No one would force any more definite outcome to it, than that the position reached was one a future buyer could potentially choose to accept. Come the sale, the buyer’s mortgage lender would not accept the problem, and pressed so in mid sale. My selling solicitor decided that a loss of £1000 to correct the issue would be recoverable, being an omission in the earlier solicitor’s work. Then a year after the event (and just after being an election candidate) he reversed position. The Law Society ruled that from a selected one of many letters he wrote 3 years before, which said no such thing clearly, I was supposed to know that his advice on the recoverability was wrong at the time when he gave it. That I should not have believed my solicitor’s advice when he gave it and he had no liability for reversing advice on a £1000 loss after the deed had been done. ‘It is to be regretted that he gave the complainer this comfort but he was caught off guard by the way the situation developed.’

‘Government cited the separation of powers for having to let this be lawyers’ standard. While to try to recover the loss from by a court route would require spending the same sum as I wanted to recover, on paying a law professor to write a report, without knowing in advance whether it would be on my side’.

The implication that no legal advice about anything can be assumed expert or ever relied on, because you could be held responsible never to have believed it! goes beyond housing. It could be very serious for vulnerable groups in court defence situations. This remains so until a profession who always prefer to be noncommittal is committal in taking the clear step of ending it: until this professional body definitely admits it was logically wrong to take a line whose impracticality for any client, hence unconstitutionality too, is unworkable when widely enough known no longer to happen in silence.

The neat good in circulating this, is that no selfish autism worker who favours shutting up bad stories can ever tell you they have legal advice against letting you write it! Can you see why? That advice itself would be liable to treacherous reversal. They can never escape from that loop except exactly by letting you write about and expose this in pursuit of ending it. Because
of that loop, and because it would autistic people and our assets vulnerable to misleading and
taking advantage, nobody can advise against writing about this. That clearly is how it should be.

**Plan ahead**
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.

Some people with autism, because of their focus, might have a particular need to live in a specific place where they will be happy. Family and other personal ties would be one major reason for this, although this is not unique to people on the spectrum. There may be other practical reasons for moving too such as employment and access to services.

‘*Because I grew up in exile in Wales I had a housing issue with being in the wrong place and the wellbeing need to have the means to migrate to the right place*.’

‘*Housing is too often discussed in a way that just accepts wherever you happen to be located, and assuming that if you have got a secure family home then can be no problem end of story. However convenient it would be to say that, it is clearly not the case when it affects folks’ access to facilities. Are they living where the services are?’*

‘*It is discriminatory against needs, including need for opportunities, to dismiss anyone who has a secure family home as having no housing problem, if they are stuck in the wrong location and have good cause to want to be somewhere else*.’

Unfortunately it would seem that trial and error still has to be resorted to overall, 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 11 Rights Benefits and 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.

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, 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 well 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.
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. Our respondents felt more unaware than aware of current information on benefits, or of where to turn for more clarity. Preponderantly they were unaware of current information on disability rights and self-directed support.

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 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 “executive agencies” (bodies set up by the Government):

- Jobcentre Plus.
- Pension, disability and carers’ service.

Jobcentre Plus is responsible for benefits for people who are of working age when they are not in work or are only in part time work with low income. This includes Jobseekers Allowance, Employment and Support Allowance and Income Support, and now, edging towards merging them into one benefit, Universal Credit, which has been long planned but had difficulties. More change may follow with some powers towards benefits being given to the Scottish government. Bad experiences have grown a lot in recent years, with private companies inaccurately finding seriously ill claimants fit for work, and potential punitive sanctionability for Jobseeker’s Allowance. Autistic claimants need an autism service looking out for how fairly they are
treated. E.g. It would not be fair or practical for Jobcentre to force a claimant with difficulty speaking on the phone, to make cold phone calls all day long to businesses with no jobs to offer who are annoyed to receive many such calls. A good service's help includes accompaniment to health checks to see they are conducted properly, and help appealing "fit for work" findings.

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. Respondents lacked information on this too.

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'.

‘I was extremely disappointed that no one spoke to me about rights, advocacy, support to gain employment, etc.’

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 autistics 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.

### 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.*

### Back up

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, but vary. They are supposed to be there to give individuals who may have problems getting support such as benefits. Predominantly respondents knew how to their local advocacy service, which is good to see.

People who act as advisers or advocates are independent of the bodies that take decisions, and most importantly are not supposed to make decisions themselves. Their role is supposed to be 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’.*

*‘Desperately need advocate now and cannot have one. Service lost funding for people without a learning disability’.*

But all advocates a need watching closely in case they apply their own agendas. At present this is not well prevented. See chapter 12: the local autism plans need to serve as an extra check upon this problem. Advocates may advise, manipulatively, that a client’s conflict is no longer worth pursuing, such that they have refused to help with it and effectively vetoed the client’s wish to pursue it. Then who is there to advocate for the client against the advocate?! - a
question to every autism service. Advocard in Edinburgh reserves final say over any letter sent in its name: this is inconsistent with the principle of helping the client say what they want. In 2011 it told a client hoping to write to NHS mental health that it refused to make any demands in its letters - even the demand (DEMAND - see page 120) for a client's safety from forced treatment - and "In letters sent on our paper, we need to maintain a detached and professional tone" meaning not asserting facts of the client's experience that had to be asserted to convey the client's message at all.

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 mysel’f.

‘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 gaps in knowledge of their rights and responsibilities can make difficult to understand when they are being discriminated against. This can leave them in a very vulnerable position. The stress and anxiety caused by going through difficult application procedures and assessments causes many to stop engaging, contributing to their isolation.

The solution to this is for spectrumites to work with public agencies to improve their knowledge and understanding of autism. Spectrumites 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?

• How will you ensure that your advocacy service, or your welfare rights service, literally represents what the client wishes to say, never vetoes it and never takes over with its own message?

• As a person with AS could you offer to raise awareness amongst professionals about your perspectives?
Chapter 12  The Autism Plans

Plan it
Each council was asked to form a local autism plan, to oversee the progress of services. They have progressed this at varying rates. This is all our opportunity for an input on any badly practising service. Parents, aspies representing our local groups where they exist, and services including the One Stop Shops, all take part in the working groups for these local plans. All have interests in the plan process's honesty. They owe us that it is delivered without letting any councils brush local bad practices off the agenda.

They are more accountable if this fact has been printed. They know that if they accept any refusals to deal with injustices in supported adult services like in the story below, they would be personally involved in prolonging hurtful wrongs able to cause despair and depression. Stronger willed aspies affected would eventually expose it. Under child safety they can not accept from the bodies, local or national, overseeing the plans, refusals to publish evidence about any child safety issue affecting local services.

Coordination of the local plans as part of the national autism strategy is happening through ANS. The coordinators obviously owe to the planmaking participants in each locality, to coordinate for them all to know of any issues around personal vulnerability and safety, child or adult, which are raised by ordinary autistic people or our family or friends. This is common sense, this is accountability for our handling.

‘An environment which has “professionals” taking the majority of places on any steering/decision making group is very intimidating even for people who are relatively confident, but particularly intimidating for people on the spectrum who lack confidence and can be swayed by arguments they may struggle to follow’.

Share it
Are we seeing ALL OUR EXPERIENCES, in specific named places and services, being put right in a directly measurable way? When malpractices are expediently left uncorrected and out of sight, the contagion of wrong can spread itself step by step. Longer than all our simple cameos because it is a chain reaction of them, this really happened:
‘In mental health charity A’s work project B, I had to make a complaint that men’s acceptance in social time was being made subject to veto by any of the women. Instead of defended we were asked to accept this even in outside life and which public events we could attend. It was never denied the project had said “cliquiness is life” (see page 61), and told me its equal opportunities policy was unenforceable in practice’.

‘The investigator left most of the complaint uninvestigated openly on grounds that to “point fingers at anyone” would not be best for fitting in afterwards - we decide it is better for you not to answer your complaint. The only person who he upheld it against, I had not made it against, a helpful student. Because not staff, she made a convenient scapegoat, and they did this behind her back without a chance to defend herself’.

‘Though I was entitled to appeal actual answers instead of their refusal to give them, A insisted this was the first stage outcome. Their procedure contained no time limits, yet A’s head office when questioned issued an ultimatum, saying appeal within 9 days or “we will consider the matter closed and refuse to enter into any further correspondence about it.” To separate complaint for doing that, A said it was their caring way of making a case progress to spare the complainer continued stress. When an appeal stage took place it was only a repeat of the same non-answers, done by a council coordinator for their Choose Life anti-suicide campaign. Neither said council nor Choose Life replied when told’.

‘A council’s social care department, the project’s funder, only began replying when I threatened complaint, and only with reasons not to do anything: said A’s complaints procedure looked “robust enough” without answering that it had not been followed in practice. So I made a social work complaint, had an advocacy supported meeting with them, then they wrote that it would not be worth making A redo the complaint’.

‘Though I was in the project under autism not mental health, I was grateful for local mental health forum C’s backing in telling A its time barred ultimatum had been unjust, and obtaining a review of its system. In return I got drawn into voluntary work in running C. A corruptly banned member’s brave speaking out unauthorised, at an AGM she was banned from, made me aware of her case and that the advocacy office running C had been answering for us to her without telling us. When the ban was proved a breach of the C’s constitution by that office, its retraction divided C into conflicting factions’.
‘Then the council changed the advocacy office, to D. Working with the faction who wanted us to be compliant puppets, they brought in new members to vote out the whole volunteer team. Next working day they got the forum’s bank account closed and its £1876 content paid to D. C was not even told in advance, 2 pro-coup members signed for it who held no office or authorisation. The outgoing advocates took part, a year after telling C that the account was secure and could never be seized. Then D proposed a new “pack” for running the forum, told us we were taking it away to think about. At the next full meeting, chaired with a roughshod shouting down, they announced that a side meeting with no constitutional power to take decisions had classed itself “a decision making meeting”, that by its decision the pack was already in force and this full meeting was not allowed to vote on it. For speaking up for following the constitution, I was called a troublemaker and put up for an expulsion vote. This when I am an intensely rejection sensitive autistic, 16 months after I had got a rule passed that there could never be expulsions, and just 3 months after through me, D had taken advice from Professor Dunlop (ANS) on working with autistics’!

‘Despite openly calling someone “weak” for protesting them, the coup leaders failed to carry any expulsion votes, but they continued to attempt them frequently against one opponent resilient enough to keep attending. The “pack” consisted of page after page of tight supervisions and assessments by D, of volunteers, and probation periods, making C no longer an independent voice, made expulsions easy and gave them discretion to refuse access to the complaints process. They failed to get anyone more than the 2 bank account seize signers to become volunteers under these conditions, so they failed ever to get the pack operating. Instead the intimidated meetings drove away attendance: within only 10 months of the coup, C shut down’.

‘Meanwhile I got no help against the coup from anywhere. The bank, wrong for accepting the signatures to close the account, claimed confidentiality to refuse to answer an enquirer who was now neither signatory nor officeholder. Charity regulator OSCR “acts in the public interest not on behalf of individuals or groups” with its own power to decide whether a seized bank account is worth bothering over. It decided it had not identified that it was “unaccounted for” or “misappropriated” or any decisions taken outside advocacy office rules, not mentioning C’s constitution, and not “proportionate or in the public interest” to take up. When I complained to D, saying that before identifying the group referred to I needed a guarantee against any possibility of resultant throwing out of it, D brick wall refused this and kept saying it would prejudge the case. So I could only complain this decision itself’.
‘No local advocacy service which does not regard group rejection as an emotional damage can fitly serve clients with social difficulties. “Under no circumstances should any one person have immunity from being asked to leave a group”, and “can not therefore provide immunity from exclusion from them even if it deemed that course of action to be appropriate which it does not”, are lines which can easily cause suicide.’

‘By some good questioning about financial honesty, 2 of us managed to obtain a meeting with social care to give a tip-off about the coup, avoiding the complaint route which would identify me to the coup leaders and allow purging. But my social work complaint on the A case was still in progress! never answered until chased. To extract any progress from them re C I needed to agree to PAUSE the unfinished A case while they checked on C - and never did anything. When after the forum’s demise I resumed the A case, they said I couldn’t. They relied on their own draft minute of the tip-off meeting, never agreed on at the time, which had B “not being a subject of further complaints”. The same social work officer, whose whitewashing over A my complaint was against, claimed the power to close down the case about himself: social work’s final answer that it has no concerns at how B is run. Chief social work officer backed him and refused me access to their committee stage: cases can not be put aside then resumed, there is no provision for this, a year after social work had explicitly asked me to do that and agreed to it. They changed their rules in mid case and lied on what they would later claim are the rules’.

‘Conservation volunteers E, suggested in place of B: team leader emailed incomplete instructions, then blamed me for not bringing footwear he had not said I even needed to own, refused to let me work and emailed that I would be more suited to E’s other local team than his. To demand to remove him, “I can confirm that this will not be happening”, faux-sorry if stops you coming. Then, encouraged by fellow member F of local autism charity G encouraged me to volunteer at ecology centre H where he did support work: “Given the disappointments you have recently experienced in other garden projects, I would like to suggest that you consider volunteering with another type of activity.” Actually in open writing rejected and discriminated against for being a victim already, and social work there won’t shut H down for it or stop sending anyone there. When F turned round and said he had not expected me to tell them so much as to “frighten them off”, and refused to stop supporting anyone to go there, social work’s brief office reply could “see no evidence of these issues” without doing any enquiries to find any. Familiar pattern? My supported paid job is in gardening, I was doing a successful volunteering at the time and have done another for 6 years: yet a place that told me to drop gardening by reason of unjust behaviour by others, is still open.'
‘Then discovered I had been ignored in G in alerting them that F’s line towards rejection experiences was wrong for volunteering with their teenagers. When not given a straight answer, circulated an email forcing the issue just before a meeting: then G’s committee rushed to pass a “code of conduct” changing their contact list’s data consent terms. Shockingly instantly in effect before members had time to consent to it or opt out of it, it cut them off from each other, cult like, from being allowed to share opinions of G or to organise to keep in contact outside it!’

‘Then G banned contact with its committee except through one spokesman. No means to tell any other committee member what the spokesman had told us, to check on what he told them, or to know of dissenters on the committee, while he was threatening libel and “alienating everyone you come into contact with, no one will take what you have to say seriously” if I criticised G anywhere. Within a year that committee became unable to get folks to serve on it, G ceased to function’.

This is how deep the problem gets when you are trying to right a wrong for the others’ welfare as well as yours. As endangerment of us is committed by anyone who says that such things can’t be written or printed, it makes autism workers accountable never to be seen exposing us to harm by blocking the exposing of all problems like these. They know the details may still surface elsewhere.

‘Adults, when not kept accountable, are totally Lord of the Flies. This started with 1 social wrong perfectly easy to fix in the privacy of 1 project. Over 4 years it led to: emotional bruising by SEVEN unaccountable complaints systems determining not to deliver, rejection for being a victim, telling to give up what has been a successful line of employment ever since, seeing autocratic coups in TWO societies which brought BOTH to quick demises, with no recourse to stop them or even to undo a bank account seizure done behind a society’s back, and being the cause of a formerly very successful autism charity destroying itself rather than fix a simple problem’.

When you are literal and logical, it is emotionally daunting that complaints systems are often corruptible and knowing most ordinary people’s cases will never be widely exposed, like to evade them hurtfully to save effort.
Even after the Fritzl cellar horror in Austria showed the world that social care departments must stop having discretionary choice over what to ignore, must be accountable for every reaction they make, yet you can still find that they uphold staff to close down cases about themselves, make arrangements to do things they will later claim were never allowed, and call funded organisations' complaints procedures adequate while ignoring them not following them in practice. It's serious when even the NSPCC will quietly drop and leave unanswered a complaint by an aspie with difficulty using the phone, who at an earlier time of trying to tell NSPCC something he was frightened about concerning child psychiatry, received an aggressive phone call full of interruptions not letting him finish sentences or tell it in the way he needed to. The NSPCC man had shouted “and in my opinion you are receiving mental health support” when the caller was not. NSPCC never answered complaint about it, after several promises and even when warned that this fact would be written.

When there is some well circulated record of exactly what serious corrupt practices are left to happen and not put right, then Pandora's box is open and no autism worker can be seen to ignore it. Any who leave us in a Angelou position (p 42) will be seen to risk causal responsibility for suicidality. Then we will see which workers genuinely care for us.

A local supported employment service which ever turns round and says an issue that has arisen in your supported job is outside their remit: with that standard of practice should they sit on any plan working group?

Some autism workers in a position to challenge Citylink on the bus pass seizure scandal emerged described in chapter 15, as a potential interference with their own work with some of us travelling to Glasgow on Citylink. They told us they were taking time to think about the best approach to it, and quietly did nothing and never mentioned it again. These are exactly the things that a good accountable functioning of local autism plans might prevent happening.

**Council tax**

Because the autism plan makers' interest is in all ways that councils' choices affect local services, it creates an accountability towards the handling of council tax. This is an invaluable advance which must be used. Local tax processes have had too much culture of wrong and arrogant testing of people's boundaries and capacity to stand up for themselves. For all our protection it needs to be under a meaningful public scrutiny.

The NAS very properly removed from its contact list a solicitor presented as autism specialised,
a "Legal Services Agency", which could give it no explanation of why it had advised an autistic person being taken to court over council tax to surrender expensively, who in fact won. The council case collapsed and was proved to be an unethical malpractice for exactly the reasons why the autistic person knew logically he was right at the time of seeking LSA's services. This was when a council had repeatedly ignored in successive years a council tax appeal and claimed to have a power to refuse to recognise it, and went on billing for the sums appealed against, though the Local Government Finance Act 1992 says that a person can make an appeal on any point of disagreeing with the council's calculation of tax. It nowhere mentions any power at all for councils to take a unilateral view against its "relevance" and refuse to recognise it.

From all the stories of missold financial products, we have come to realise advice should never be simply trusted without analysing what you think the advisor's agenda is in giving you it. So autism workers and books must not recommend us just to trust advice from standard sources. Not even Citizen's Advice Bureau, when you know they did not match NAS's care on the above case and they can write: "as the LSA are not part of CAB service we can not and will not answer your comment about their organisation. There would appear to be nothing else we can say and CAE considers the matter closed."

This situation had even been allowed to arise thanks to a council supported money and debt advice office, advertised as ethically independent from the council. When brought this problem they had determined at all costs to remain cynically noncommittal on the fact of law and not admit the council was doing wrong, and when it ended in a complaint, admitted they would not come into collision with the council who funded them - who they were publicly billed as independent from!

Unless folks who read literally are supposed to read laws literally, then there would be no law and no public office can ever expect us to know how to function. While we must remember also to challenge the simple reading and accepting of a law that conflicts with the literal reading of human rights conventions - such as the council tax summary warrant system, which does not provide for a defence case to be heard. So it would be wrong to just accept that system and wrong for any autism worker to be overawed by it and tell an autistic person to accept it.

It follows from this and the case just described, that they give every council a duty to include in its local autism plan a total ceasing to use the summary warrant system. No local autism
An Ordinary Life Too

plan is human rights compatible unless it includes this. All autism service workers dealing with
a client’s council tax problem, because the client has human rights and a protection against
taking financial advantage of, your duty to them is to hold all councils to this standard. Clearly
it helps you when you network about this and know you are not alone in this position.

Access it
Holding occasional meetings with the charities and other stakeholders has not been enough to
keep local authorities liaising with providers and working together to sustain sensible
outcomes. Budgets can still be locally erratic and cuttable. The increase to 8 local One Stop
Shop services, under the national strategy, was intended to be progress towards getting all
Scotland served. As the 3 year start-up funding help given in the autism strategy expires, some
of these well valued sources of help with coping needs as well as social spaces are already
being lost again, along with jobs: failed outcomes for a successful facility.

Motherwell OSS, covering the 2 Lanarkshire councils, closed upon the end of that funding
despite good newspaper visibility of the families campaigning to save it. 6 months ahead of the
expiry Scottish Autism had been pursuing council attention to securing its future, and received
a reply on the day of funding expiry! North Lanarkshire has simply suggested as a substitute, to
support a local charity which has waiting lists.

‘Light should be shone on their shenanigans, exposing the sham which is replacing it.’

Aberdeen OSS is closing, both councils choosing to fund “autism friendly projects” instead, a
rather less definite facility. Fife's OSS has had to downsize from its original premises and lose
open social time, repeating ARC's experience in Glasgow.

‘It has been an absolute lifeline for me and many others, we have the One Stop Shop Albion
House run by Autism Initiatives, have been instrumental in accessing and improving services on
behalf of the autistic community in our area’.

A slight majority of responders were aware that their local autism plan exists. But they said
they had not had opportunity, any or enough, to influence the local plan, nor knew anyone who
had.

‘I've suggested ideas to help with a very limited budget but they are not interested’.
‘The constant focus of people’s attention and the resources available have been on early years, school age children and young people at the expense of the vast majority of the autistic community. I do recognise the need for working with children and young people, but others involved in developing interventions for the autistic community need to recognise that we are adults for far longer than we are children. Failing to address autistic adults’ needs now simply means the children heading for an unfulfilled adult life of suffering, social isolation, and neglect. There needs to be a better balance. Middle aged autistic people have suffered enough in their lives; it’s time to give them a break’.

From where I’m sitting the involvement of autistic people has been tokenistic. I suspect the “service users” are there to give credibility to the decisions that the professionals want to push through.

How shall the planmakers prevent this picture and convince this contributor otherwise? Only by there being a means for the autism grassroots to follow up, and make known, any experience by the autism grassroots where participation fails to be visibly effective. It will not do to send a council official to visit autism societies for a listening exercise, and refuse to answer about specific bad services on excuse that nobody from the service is present to defend it. Accountability visibly to grassroots level means a continuously existing outlet for the ordinary autistic person. Our participative ANS Asperger Forum has shown this need and served as an outlet by publishing this chapter.

**Summary**

Local problems remain unsolved when officials can persist in being noncommittal. Closed circles of discretionary power keep us vulnerable to malpractices and blocked from redress, unless anyone caring about a problem will always have an outlet to write up the details and circulate them effectively. So the national coordination of autism plans always needs to include this route of accountability.

Problems revealed and written up show when there is more which the autism strategy and local plans need to work on, and whether they do it.

**Reflective Questions**

- Do you know who is working on your local plan? Are they listening to your concerns?
- Has your council yet produced an autism plan it can show you?
- How comprehensively does it cover local autism-related life, and sustain it?
• If you work in an autism charity, what cut corners and rebuffings of issues could be prevented,
  (i)  by your charity taking part in an autism strategy and plans?
  (ii) by yourself taking part?
Chapter 13 Computers and 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.

Cameo 1

_I much prefer to type than talk. Online I can meet others and network. I can discuss 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 into social networks as well as constant use of mobile phones, blackberries, i-phones, i-pods, i-pads, 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 or 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’.

‘The speed at which new electronic technology becomes redundant is ridiculous and I have actively chosen not to be part of the constant cycle of renewing and upgrading technology that works perfectly well just to have the latest innovation.’

For the older aspie without a background in electronics, modern computer technology is unfamiliar and can only be learned in manageable bites. It is disorientating to wade through many jargon terms they have not grown up with. This problem makes less learnable the details of how to use the web. Age’s physical burdens, like stiffness or arthritis, can cause such a random problem as finding library computers suddenly updated with keys whose design is wrong for your hands, so that hurt fingers prevent prolonged use. Then where shall the elderly person get advice, that is simple and not technically overwhelming, on finding a computer they can use?

‘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.’

Taking the Plunge

Aspies themselves differ greatly in coping with owning computers and internet connections. This is no problem for those with a strong IT knowledge and interest, who have followed computers and programs through all their developments. Others say, that yes, computer shops blind you with too much science to take in, but it works out if you buy and take pot luck, you will get a standard usable quality of web access. But for an aspie who is nervous of getting a big purchase wrong, and not familiar enough with how to buy the right compatibilities of computer and router and server, it can be too hard to take the plunge and buy. That means choosing instead to rely on going out to libraries and shops.
'A further worry is whether any effective support will be available when a bought computer malfunctions, from either the maker or your chosen web service company, and what to do if support by phone is ineffective or grumpy. It is a difficult purchase, which it would be good to have some local support and guidance for. If getting help from friends, such as in an autism society, it matters to consider everyone’s advice with your own cautious judgment, don’t let someone keen to feel like the expert take over your choices.'

The emergence of tablets now offers an economic alternative to full-scale computers. Tablets are less usable for doing a lot of writing on, or editing documents, but they provide most of the desired features of web access. Tablets, I-pads, or laptops can all be used to access the web when you are out, without needing a connection at home. They connect to the wifi signals that are now provided freely, but sometimes erratically, on buses and trains and in or near some shops. The drawback is the need to discover whether there are any good shop wifi signals near your home, if this is not near a city centre. Once you have a tablet or I-pad, you might then find a good deal for getting a home connection. It is easier now that deals providing a wireless router, a device that creates a wifi signal inside your home, are replacing the older complexly wired modem devices.

Finding solutions one step at a time like this may be the way gradually to improve your access to the web.

Easing social contact
The virtual world of the web 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. Information processing, gathering together what you want today, responding to expectations and managing the timing involved in day to day communication, can be a pressure and frustration. Email and other virtual communications can allow more time, and space, to focus and get it right, so can be more 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.’

‘Much easier to email than use phone. My preferred method of communication as don’t have to speak to people.’
"I find the phone very difficult and uncomfortable to use, emails and particularly texts are very useful."

"Written replies etc are easier to take time to think about - I don’t need to see or meet people'.

"It's easier to communicate behind a keyboard, than real life.'

"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.'

"It’s great for shopping and for finding out about places and groups before going there."

"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).’

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.

**Online social networking**

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

‘In family tree site Ancestry, invitations between members can only be accepted once, and are lost if accidentally accepted to the wrong member. Unless you had note of the inviter’s member name, this accident could leave you devastatingly cut off again from an unknown relative who found you and made contact, frantically asking their customer service to help trace the member, and running into them raising data protection objections. At best, to be able to contact the member you would have to become a subscription-paying member for a while yourself. So you need to be able to afford that even if you are not intending it, before feeling safe to use Ancestry. It is not fixing this fault’.

To the public inconvenience when libraries convert their computer services to an unfriendly system called Netloan, councilors are reluctant to answer users’ stories or argue with library services’ opinion. Its issues include really brusque messages of “you are not allowed to log in” when you are outside the time control, and the automated timeout happening unexpectedly, by drifting out of sync with the screen clock or spontaneously by a system fault. You have to gauge from experience how to juggle the stressful dilemma of having to get up and go to ask for extended time and wait for service while the time you already have is ticking away. This is worse on days when the system runs slow.

**Cyberbullying**

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.
All of our survey respondents said they used the web to communicate, 3/4 had experienced it as positive. 1/4 considered they had encountered cyberbullying. Research highlights that in reality people use the internet to reinforce their own ideas and don't like to have these questioned.

'Best thing really is just don't engage: stop answering their posts or messages.'

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

There is a danger in the way that forum sites and messaging groups have developed. They have been designed to let their hosts deal with trouble easily, by the power to throw anyone out of the group, ban them, at the click of a mouse. Contemplate how serious a blow this is if it happens in a group actually recommended in an autism book's list of online resources, so how vulnerable readers need the publisher to react to any such occurrence. For all who have found it difficult all their lives to gel with groups successfully, to catch the mood right, any rejection experience with a group closing ranks behind a dominant figure is a further scarring trauma, tearing apart all confidence to relate to anyone:

'Challenges to views are easily drowned out. It's a way of creating online in and out groups and those in the out-group can expect sidelined. Facts get lost amid assumptions and perceptions from what a group want to believe.'

'My daughter had to block someone on Facebook for a hate campaign.'

'It is important not to give away too much personal information online'

'Stay off social media when feeling vulnerable, angry, very emotional.'

Political Facebook groups have been notorious for this in recent times. They can easily be created by a single host who then acts on whim, or they can claim to be discussion/debate groups while only allowing one side to be heard. They show how online spaces can be cliquey in favour of their owners. A forum site Wikipediocracy, critiques Wikipedia and is a resource for all who have taken part in Wikipedia and experienced easy banning, and fierce faction fights or arbitrariness by the "admins" over pages' content. It shows that many have suffered there. Though a participative encyclopaedia sounds an autism friendly idea, the practice is seriously
not.

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

Thankfully now defunct is an aspies’ forum site with an ambition to be a global movement, which became notorious for easy bannings, even of folks who had helped it and worked to promote it, then found the leaders would unexpectedly take against a word. Or, a forum may change in character over time, become more rulebound as it grows. The main strength of the online Asperger scene is that it is not focussed on one forum site, that there are several to try out. Folks can come to know each other through 2 or more sites at once, which is good when you need to regroup when any one site goes rogue. The British Isles forum scene has let to aspie meet-ups and holidays too, good real life connections.

Email problems
Choosing an email service includes stressfully researching online reviews on the too often lack of effective help for faults, and whether the spam filter is too strong or allows you to see the filtered out emails in case you wanted them. Emails that are long or have attachments or multiple recipients, which the email hosting companies are wary of because of spam, when sent from tablets or mobile phones can unexplainedly sit in a file called an "outbox" and not send straight away, and have to be resent when you think they have just got stuck there. This affected us in compiling this work.

When composing any long or important writing online, always save 2 copies of it. It is good to be able to save it as a draft in 2 different email accounts, or maybe save it both in email draft and on a memory stick. This is because there are awful possibilities of losing a text while you are doing things with it. Email drafts can pick up invisible and unwanted formatting codes lurking at the points in the text where you paused your work before, and can cause blocks of text to vanish when you go back over them. Or you might accidentally delete a draft, or save it with some content missing after editing it. It can become a traumatic and miserable experience unless the tip of saving back-up copies is picked up as a habit.

It has become a frequent frustration, shared by many folks, when we change email address: that mails persist in going to our old address. The sender’s email account persists in
remembering and trusting the old address, as one regularly sent to. It prompts the old address to the sender, who can easily forget you have changed it and accept the address prompted to them, or not even notice it is the wrong one. In a circle of folks mailing each other regularly, after one makes the error the others copy it unwittingly. This is clearly a design flaw in the world email system. Old email accounts then inconveniently continue to need checking, unless they can be shut down. But what if your old address is not working properly? Then it becomes really important, and infuriating, to have to persist in correcting everyone back to your current address.

‘In a BT email account which malfunctioned from the moment BT ended its old contract with Yahoo in 2013, no emails were arriving, yet they were not bouncing back to senders either! It took a lot of phone stress, hour long calls to a helpline who kept expecting me to have a home computer when the service contract did not require it, and even after being told there wasn’t one, kept repeating the error of demanding to do a “screen share” with a non-existent computer to do tests! It took itemising the circular repetitions of this to stop BT keeping passing me back to the helpline, and force a complaint for their business office to deal with.’

The fault was only understandable to IT buffs: “There was not an alias built on the server recognising your account. Once this was recognised and built you were able to send and receive emails as normal, so unfortunately any emails presented to your account during this period would not have been received for which I apologise for.”

This in a service that had become paid for. Many ordinary consumers of email will be horrified to hear this can happen, yet computer buffs were not surprised at all. A source called “RFC 5321” on protocols of the global email system: “Utility and predictability of the Internet mail system requires that messages that can be delivered should be delivered, regardless of any syntax or other faults associated with those messages and regardless of their content. If they cannot be delivered, and cannot be rejected by the SMTP server during the SMTP transaction, they should be bounced … dropping mail without notification of the sender is permitted in practice. However, it is extremely dangerous and violates a long tradition and community expectations that mail is either delivered or returned. If silent message-dropping is misused, it could easily undermine confidence in the reliability of the Internet’s mail systems.”
Possibilities

Individual taste and interest plays a part in how technology is viewed - for most of 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.’

‘My neighbours and I were able to arrange a communal roof repair by email’

‘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 harm?
Chapter 14 Consumer issues

Directness of language and alertness to read between the lines are key features of obtaining services successfully, both social and bought, and shopping. These are harder when communication is not easy flowing. So workers in autism need to anticipate that cause will arise to give sympathetic support with this, even for the more self reliant of autistics. As consumers we all have to try to be aware of potential tricks and hidden problems, and this is harder if we are wired to take literally what we are told, or we have not always picked up a streetwise awareness of what to look out for.

Thus consumer problems appear in many of our other topics too: in housing, digital, community inclusion, mental health, and even using support services (chapters 11 and 12).

Using the phone is a cause of great nervous tension and struggle for some of us. It carries an immediate pressure to speak, to an unseen voice. We can't sustain that if we have slower response times and only know what to say after careful thought:

‘Talking to people especially in person or on the phone can be difficult + frustrating’

‘Often they have already started saying “hello - hello - are you there?” faster than I can form a sentence and start speaking. They can keep throwing their line back at me in a well trained clipped voice and interrupt if my drift is not convenient for them. I find they often get impatient when I have any trouble with saying exactly what they want to hear, and at a pace of glib speed that I can't sustain. I have to cut in and argue before they make a pretext to end the call, to have any chance to pin them down’.

‘Go to the bank, for safety; I don't trust online banking’.

‘by phone and at branch’

‘prefer online. not always possible’

The problem of phoning can be necessary to the process of setting up services for landline or mobile phone, home internet, or TV service. To check on the service's details, or to answer their questions on your home's telecom connections, can require talking to someone on the phone. If it is daunting to set up new contracts for these services, it can be too confusing or time consuming to sift through details of services and terms to find the best deal:
‘Exhausting’
‘I have often gone with familiar/least change rather than getting best deal’
‘Endless calls to unsympathetic helplines’
‘Usually not too bad by doing research on the net first’
‘Pay as I go. No contracts. Too confusing + don't trust them.’

Trade in
‘Read the meter is fine but sales men is worse as they will not take no for an answer.’

For autistic people, coping with tradespeople visiting the house can be very nerve racking. There is a fear that showing nerves increases the chance of getting cheated by an unscrupulous trader. Often they can appear to be more vulnerable than someone who is NT just because they are processing the trader’s speech at a slower rate. Neurotypical people sometimes have learned to pick up on this. A slow person may be thought less likely to challenge the worker if their job is not done perfectly.

‘I don’t mind small talk and can enjoy it if I'm not too stressed, but I cannot cope with the comedian types as I can never think of witty replies and I get upset and frustrated at coming off worse in my own house.’

‘I hate people coming into my house for any reason. I have a fear that tradesmen will simply do a bad job and charge a fortune and I won’t be capable of stopping this. It is a serious problem that has prevented me from getting work done on the house for years and there are now a number of things, some quite serious, that desperately need attention but which my fears are preventing me from dealing with.’

‘A team of joiners managed to make it last 5 weeks by coming in and out to do small bits of the job rather than just getting it over and done with. The arguments to get the job finished seemed endless, they blatantly lied to me on many occasions. What is most galling about this is the way in they seemed to treat messing me around as a game where they clearly had the upper hand (I needed the work done and once it had started it was difficult to bring in new people to finish it) and they knew it. Why people can’t just do what they say they’ll do, or in cases like this are contracted to do, is beyond me. The palpable pleasure that they get out of “getting one over” on you is what really makes me sick to the core of my being. It is a form of mental harassment and seriously impacts on people’s lives and their health and well-being.’
The fear of having no consumer leverage to enforce good service can make necessary a lifestyle of patching up and making do, to minimise as much as possible any use of tradesmen or risking of big new purchases. Continuing to use partly broken items, doing your own ad hoc repairs of holes, using a tape measure to select a curved twig from a tree to unblock your toilet. An observer who is a more skilled consumer might then criticise the aspie's living conditions.

It is surprising how pitfalls can be lacking in public awareness, that would make life easier for the struggling literal minded consumer of furniture. In some right angled joints in furniture, wood or metal, they use a part called a “dowel”, which is a short stubby pin that is embedded into a larger object at both ends. They clearly have to carry more weight, than nails and screws, embedded at only one end, a dowel holds 2 parts together in a way that leaves it entirely hidden inside the joint, a bad idea if the dowel snaps. There is no way, easily if at all, to extract the embedded snapped half, flush with the surface surrounding its break. The whole object is left ruined, wastefully, if that happens.

Stories can easily be found online with the likes of small tables, drawer sets, chairs, cots. Knowing that, you might look at the joints when you buy such items. If a bed is made with dowels that can break, is it safe to use?

A contributor here got a new bed returned, using this tip: asked the company to explain how the bed could be safe in the face of the evidence of a quickly broken dowel joint? More daunting for them to answer than to accept taking the bed back. But this tip did not come from trading standards, who seemed wary of being the source of factually questioning a product’s fitness. It took a lot of coping with phoning to solve that one. Unseen before purchase, the bed also had come unfairly with advice that not all purchasers would have the means to follow: against assembling it alone.

**Shopping**

It pays to explore and get to know the range of shops around us, to get some idea of where to buy household goods and clothes. Shopping around only when we need an item can be a pressure and time consuming. It is hard to keep track of products changing and disappearing. We need a choice of shops within reach, to let us find which are least uncomfortable in spatial feel and attitudes to customers.
If an item's price is not displayed, it is embarrassing to ask it then decide not to buy because it is too high, especially at a local shop you intend to go to again. Are we willing to guess its likely price, when prices can vary widely? We may decide not to buy unpriced items, as a practicality and a fairness to customers too, and to avoid shops that make a habit of hiding prices? But what if the only corner shop in a remote location does this?

Consistency of shops in selling the same products becomes part of life's coping routine to spare the effort every time to think out the steps of what to buy and where to find it. This security is exploded when a familiar product vanishes from sale, without even announcement, as food brands or household goods often do, leaving a sudden gap in our life coping cycle and panic need to hunt for a replacement, unsure of finding it. Products' names change too.

If searching for soap in a pharmacy, and all that caught your eye were items called "beauty cream bars", would you know that was a type of soap and you had found the soap shelf? That green "household soap", for kitchen and fabric washing uses, is disappearing, even from the household goods shops. If you are accustomed to it because your family used it, how can you know what to use instead when you can no longer get it? How much of your life can you waste hunting it?

With occasionally bought electrical items, phones, radios, kettles, it is easy not to realise how easily our awareness of their available range and prices slips out of date, and how the types of shop that sell them have shifted. It can be very confusing where to buy occasionally needed household items if you suddenly need one and have no mental map of where to find it, and shopping around is time consuming. Maybe you learn from this experience, to observe what types of household items you see for sale and where.

A female aspie suggested accompaniment in clothes shopping, to advise on choices that look good. Contrast this male experience:

‘In youth always felt I might be buying unnecessarily conservative shirts just from not knowing where to find the most colourful ones. Family were most likely to go to M+S or similar, not the style I wanted. Only over time I've managed to find and buy wonderful colourful light summer shirts. My sensory issues make buying sweaters and jumpers difficult. We should always try them
on. Every garment is different, sometimes the weave has a relaxing lightweight feel, sometimes too stuffy to wear all day.‘

‘What if you are not transgender or gay, but ragingly driven by sensory issues to have the same personal liberties as half the folks around you over arbitrary one-off details of your looks? Since liking and buying a pink watch I have found there was nothing to fear and feel very freed and empowered wearing something that has no rational reason to carry a gender assumption. I find it oppressive that for no physical reason there is a cultural rule that my gender can’t paint our nails, but because of it I have no experience and no idea where to start in trying to get any gear for it and making judgments on quantity, durability etc. Could a shopping supporter solve that? and help with finding the situational coping limits, e.g. bus drivers who already know your face.

Eating out
Our slow and precise pace of dealing with information creates a potential problem over food and drink menus, maybe taking longer to make our minds up carefully on every option’s merits than keen serving staff would like. Then those moments when they say they have not got the item we want, are particularly difficult because they expect us to give another choice instantly, and how to find words to push away that pressure without getting into a clash with them. Leaving in a huff may be the only resort to escape an unwanted buy. In such situations when with a social group, they may expect you still to buy something in the place the group has chosen to enter. It matters to avoid that trap, or to stand up to it. Sometimes they turn impatient because they just want you to be a simple customer who only chooses the obvious instead of choosing what they literally offer, sometimes because they are being too helpful and jumping to conclusions and going to fast for you. e.g. In a chip shop in Balloch:

Cameo
I think my first mistake was to wait politely until she had stopped pouring the vinegar before speaking up to say pickled egg. It seemed pushy to go for it while she was still doing the vinegar. "Bit more?" The vinegar is fine, really - "that enough? More?" No. Now both sounding defensive. Because she had cut across me I had stopped speaking again, because I had stopped "I can’t hear you." Now she was annoyed. Managed to get her to hear egg, she went to the pickle jars, looked back: "Egg or onion?" "Egg, yes." Opened the egg jar, looked at it doubtfully, closed it again and opened the onion jar !!! Why!!! "EGG!" "Calm down!!" Paid and ran like hell.
Maybe chip shops pose this sort of risk because they are downmarket and brash? Yet their menus are far simpler than posh restaurants', logically less cause for problems. One in Dumfries: oh we don’t sell peas any more because nobody buys them: yet they had kept them listed on the menu. We are likely not to want to be challenged with cultural banter over our food choices, put on the spot to defend them, that discomfort is rather threatening, not service: as for an aspie holiday party having fish in a sea front pub in Oban. Told: “Ketchup? You heathen!” Huh?

You can feel deceived, and not in control, to be drawn into a buying pressure by advertised items that are never available. Menus often don’t say when parts of them don’t apply for the whole day. e.g. supermarket cafes still with glowing billings for bargain salmon meals even when they are going to tell you they have none left. A bakery in Rosyth displayed a whole menu section of filled potato meals never served in that shop at all! Why? oh these are the standard menus printed for every shop to display. Then pushing forward a potato pie without mentioning it contained meat.

If we want to have more care over our health and our money than just to copy our friends’ tastes, then in group dining it’s usual for us to pay for ourselves and to dislike having one group bill, with its awkward swapping of change and having to contribute to others’ expensive choices. But bars and restaurants often prefer a group bill. We were easily all agreed not to go in a sea front cafe in Arbroath with a sign "no split bills".

Who cares?
Autistics of all ability levels need access to consumer type support from within our scene. The media are not enough of a safeguard, remote and selective in what their consumer outlets will respond to. We see next chapter that as complaining consumers of public transport we are not well protected. Autism Network Scotland (ANS)’s own existence, and through it a direct outlet for ordinary aspies’ concerns, has already mattered on a big scale to address the consumer problem some of us have felt towards autism charities: that they would choose for themselves what to talk about on our behalf, but not always take up our concerns.

It can seem to charity leaders an easier life to just put out upbeat PR and stay popular with councils. We are all consumers of the autism charities: so our consumer agenda to them is for their cooperation with pursuing our service problems which are big enough to involve human rights. It hurts and undermines us, as adult consumers of autism services, as well as being a shocker towards children, when a big charity’s Scottish leader tells you to your face
You won’t like it…” that he is consciously choosing not to include in their literature the issue of aspies whose chance to be child authors was cruelly destroyed. It lets us down as consumers of services, when the charities do work in creating employment, and say oh look how wonderful we are for it, without saying a word against work dress codes that would clash with our sensory issues.

When you suffer a consumer wrong from a big service that matters to wellbeing, there can follow a trauma of cynical voices not wanting you to spread the story or obtain answers. Anyone with a logical mind and sense of injustice, both associated with autism, has the distress impact of a consumer wrong greatly magnified by the insult that uncaring people want us to just forget about it and live in acceptance of the loss. This is a kicking when we are down.

With private sector provision of some services now, their users seamlessly become consumers. The law of adult protection is supposed to apply against taking financial advantage of a person’s vulnerabilities, which include autism affecting communication, and tricking money out of them - including by tricking them into spending on ineffective or harmful items. There is a tension and conflict between this law and the common unpleasant practice of telling a wronged hurt person: no no you can’t write any bad things it might be defamatory, you can only write about nice cosy positive things. That convenient catch-all device of calling it a defamation risk ever to write about anything bad, creates a culture of silence and selfishness, which is used frequently, both by voluntary associations and by career building professionals, to quietly bury problems instead of dealing with them.

Lawyer’s answer
This can fall back onto their claims to rely on, or to need to take, legal advice: always said knowing they will get the advice they want to hear, because solicitors will always advise avoidance and cynical noncommittality. Oh but it counts as expert, so it must be unanswerably right, right? No!

There is a deep consumer problem with legal advice, and not just that it is expensive. To be reasonably critical of solicitors’ opinions, instead of in awe of them, can be necessary to an emergency intensity. That makes it a duty to vulnerability that any autism worker must side with an autistic person who stands up to a malpractising breach of trust in an emergency, and must not tell them the solicitor is bound to know best. Different consumer dangers with solicitors are shown in both chapters 10 and 11.
Clearly solicitors’ duty to autistic clients is to use definite enough language to prevent future trick interpretations. It is a fair duty to all clients, but for us it is part of the duty to let us read language literally without having to guess contexts for each word. If lawyers should be willing to explain any word meanings asked for, then so should an autistic who is writing about a consumer experience with lawyers. We need to write knowing that other autistics will have that need when they read it, and be willing to clarify words when asked. But, the writer has a need too - we must recognise that the writer is stuck with using some legal jargon words to explain what a lawyer did or failed to do. That is not the writer’s fault.

It is a long standing consumer problem with lawyers, that they have their own world of technical law terms that put a wall between them and a let down client. That barrier is only strengthened if a reader who finds the language like “a cryptic crossword” blames the writer, instead of the legal system, for this.

**To clarify?**

An autistic whose confidence is already knocked out by a consumer injustice, and tries to do something about it, suffers a further unjust hurt and debilitating blow to confidence if another autistic blames them for trouble understanding the words in a consumer issue. Only the offending business benefits when that wrong happens. Any caring listening friend who needs details clarified will ask for it, item by item. A character who only wants to hear casual chatty concepts, and not understand consumer problems until they suffer them personally, is by choice less aware and easier to rip off.

So if someone rants hurtfully to you about not understanding, or calls an important concern hard to understand, ask them to pick out exactly which words they want clarified. When they refuse and won’t be drawn to do that, you have proved they are really refusing to listen, using the device of not understanding as a nasty barrier to communication lest they have to react to what they hear. It follows, as a consumer standard for all autism services, that autistic folks of all ability levels need this rude device not to be allowed to exist when we describe problems.

**Summary**

Lacking communication skills makes us either be, or appear, more vulnerable to bad service. As consumers we can be unconfident about confrontations and the learned tips for prevailing in them. We may have to choose to avoid buying certain goods or tradesman services which take us out of our coping zone, but we may find we can't always avoid them and get by.
Regulators and solicitors can be avoidant of confronting anomalies. To prevent taking advantage of us, there will always be a need for access to autism friendly support with consumer problems. But consumer services' own reliability + care to get it right can be a consumer problem itself.

Reflective Questions

• As an autistic person, how easy is it remember that sales claims should not just be taken literally and need scrutiny and checking? Do you hold that in mind as a plan to follow?

• Do you, family member you support or who supports you, know where to find trading standards support? How do you/they feel about putting a problem into writing or phone speech to them?

• What do you prefer to do when a shop or cafe does not give the service you want? Go elsewhere, argue, accept, or combinations of them? How do you approach being out with friends whose preferred reactions are different?
Chapter 15 Transport

Autistic people are often drawn to maps and transport networks and acquire good regional knowledge of them, because it is a reassuring exercise of putting the world around us into an ordered pattern. What a frustrating irony, that for most this strong point is outweighed by the many perils in communicating successfully with too briskly efficient or grumpy transport officials unwilling to take it gently, and the unclarity of what to do when travel goes wrong.

‘I have developed a system of travelling which basically leaves so much time between connections that I can't possibly miss them. It does mean a lot of waiting about…’

‘In north Scotland things deteriorating fast, no one is looking after it. Losing faith in public transport.’

The shared confined public space aboard public transport has a potential for sensory upsets: overcrowding, penetrating voices chatting about annoying topics, music leaking out of headphones, loud onboard announcements.

‘At certain times I can feel a little fearful of who I may encounter on public transport ... the police do not see drunken young women physically abusing a man as serious while a man behaving similarly towards a woman would undoubtedly be arrested. There is basically a sexist attitude...For the record, I find being randomly molested by a woman as deeply disturbing and distressing and am angry that the police fail to take appropriate action.’

Trains
Ticketing arrangements are often inconvenient for passengers. The railway is totally unsympathetic if queueing time results in missing a train, after maybe road delays, or to anxiety when they expect you to use a ticket machine at an unstaffed station with no one to see if it goes wrong.

‘Early last train home prevents accessing a lot socially
The complicated layers of train fares and companies now defeat all types of traveller. Keeping it difficult on the busy lines helps them to reduce travel demand when it is increasing faster than capacity:
‘It is now 13 years since I used British main line railways and from press reports it seems train travel is exceedingly uncomfortable and trains are SLOWER than in steam train days! But above all else the privatized companies are quick to penalise anybody who MISSES the stipulated train he is supposed to catch therefore people are MAROONED and PENNILESS if connections are missed. As I suffer from a concatenation of medical conditions that can severely impair me if not treated promptly I have a justified fear of this incapacitation far from home.’

**Transport complaint systems**

How well are we protected by them? in 2006, when a fare was the same to 2 stations Scotrail would not budge from insisting that a ticket could not be used returning from the other station. Yet obviously the passenger has fulfilled contract by paying the right fare, so it is impossible for such a rule to exist:

‘Exiting at Dunfermline, barrier staff insisted on selling only to there, refused to sell it to the next station. Felt untroubled knowing the fare was the same, only to find the conductor called it wrong when I returned from Queen Margaret, from an evening autism meeting.’

‘4 Mar 2006 to Rail Passengers’ Council. ‘I notified my intentions to British Transport Police on Jan 15 and I copied it to you, so… I could refuse to obey any order to leave a train… On Jan 17 I made the journey, deliberately got a Dunfermline ticket, then paid all my remaining change into the bank, and deliberately made my return journey from Queen Margaret carrying a Dunfermline ticket, no money at all, and copies of” letters. “I had no problems with this conductor at all, concerning the logic of pairs of stations to which the fare is the same.’

‘This action taken because phoning Scotrail after the incident had just got “That’s the rule and I can tell you they won’t change it.” After this action, as if it had been a waste of ink, still repeated that they would not accept the ticket interchangeably. Hence complaint points:

- holds itself entitled to deny that a journey is valid where there is no unpaid fare
- doing nothing to prevent it being possible for passengers to be placed in this position by barrier staff,
- When a rule is proved unsustainable by the anomaly it creates, contractually and in the criminal law of valid travel, the company does not alter it or acknowledge its voidness
- refuses to comment any further when legal issues are knowingly left unanswered
• These things affect a medical interest group as well as a person singly.

27 Apr 2006 Passenger Focus: “I appreciate this may seem nonsensical, but it is correct. I’ve discussed your case with the Customer Relations Manager, who has advised there has been no policy change.” Without offering any answer at all to the reasoning from the travel contract, and ended, “I can only reiterate the advice you have been given before, and that is to purchase a ticket for the complete journey that you wish to make” - without mentioning at all, any more than had Scotrail itself, that the barrier staff had refused to sell that ticket.

A body supposed to help complaining passengers simply chooses to accept that any rule exists if the company says so, and not answer when a passenger with no unpaid fare demonstrates that this rule and policy do not exist even if Scotrail says they do, and everyone is entitled to ignore them. Because in any situation, siding with institutional expediency against logic is capable of triggering suicidal despair towards life, the whole autism scene will always continue to be obliged to uphold the non-existence of this rule in real travel situations whatever the rail company says.

Compare with good practice in a bus complaint -

‘A bus sat at Halbeath park-and-ride without displaying any destination, until just as driving off! then was angry when I rushed up to catch it, blamed me for not knowing which bus it was, and regretted instinctively stopping for me because that was supposed to be against the driving rules. Destination not displaying until the engine was started was a particularly bad design fault on an airport route. As the driver had done right by stopping, had not left me behind, it mattered not to let him get into trouble for that. Succeeded. Stagecoach: “Yes, I can confirm that on this occasion no action has been taken in regard to his stopping outwith a designated place.”

There was a good autistic sense of fairness, good practices by complainer and company. It’s worth remembering that sometimes the driver needs standing up for too, against practices conflicting with common sense to the passenger. That helps with getting better outcomes.

2007: First’s drivers often not bothering to know all their zonal fares properly and using guesswork, one refused to sell the fare asked for on my way to work. He actually took a £20 note for a weekly ticket then denied that the ticket for “LM” zones existed, insisted I should want “LMN”, and refused to give the note back, while other passengers were not making any
effort to understand his wrongdoing and were calling out “take your ticket”. He was not sacked.

The bus complaints system, then known as the Bus Passengers’ Platform, shared some features with the complaints systems in chapter 12: it would not answer generic enquiries for its line on a complaint of a particular nature. It would do nothing to tie down its response until an actual case is complained to it. Then its answers show exactly why you wanted to make those enquiries: “the committee cannot uphold the complaint that you have been treated poorly by First drivers as there is no evidence to substantiate this”. Forcing an unwanted wrong ticket onto a passenger while physically holding his money and refusing to return it, and driver intercom later having to authorise another driver to change it, is not evidence to an “independent body”. Then what is?

The present body is Bus Users Scotland. As ever for these bodies, it declined to comment when asked, and declined on principle to answer generic enquiries. It asks to say that it works “in partnership with lots of stakeholder groups” for vulnerable people, takes all passengers’ safety “very seriously”, and “We advocate that buses should offer a safe and comfortable environment for all passengers to travel on.” Decide for yourself whether you accept these vaguenesses from a body that will not say anything committal. Without the answer which both these regulators refused to give, no autistic person can ever reasonably be expected to catch any bus when fare paying: for we need to be safe using our money.

Highland Council had a “Service and Information Point” in Golspie: it carried out a model good practice when a northward bus was 2 hours late. Instead of being stuck in uncertainty without info, dithering what to do, taking literally this office’s rare broadness of description encouraged me to enquire there on traffic problems. They phoned a traffic info source and learned of a road problem further south then they phoned the bus company alerting them to me. It was still not a happy ending, because the company accepted the message as if to pass it on, then later denied to me it has any means to pass messages to drivers - when we all know drivers have an intercom with their depot. So when the delayed bus appeared it still sailed past, catching me in the offside hailing position coming out of that office.
Despite that, look at the good practice in how this council office tried, looked out for a disrupted traveller’s way out of trouble in a remote region, and how finding out what was happening made him safer.

**Bus passes**

The concessionary passes for free bus travel are a big social benefit. They simplify their holders’ lives, less by not paying fares, helpful as that is, than by not having tickets tied to one bus company and to sort out complications of fares. Local buses become usable in a far more sensible way, when you are free to use any company’s bus. You can follow the actual pattern of all the services and most direct way to destination.

Passes do not leave the holder with no worries, because like ordinary tickets they are still losable. Passholders still face driver trouble. An old lady shouted at and called a liar over a replaced pass. Why did a driver tell off a passholder absurdly, that “it does matter” to ask for a through ticket he did not know existed, from Dunkeld to Pitlochry, instead of using his pass separately on 2 buses that connected at Ballinluig? On Orkney, a driver get really angry because asked for Stromness instead of for Hamnavoe district within it? Both expected non-local passengers to know local practices.

‘I have experienced scepticism regarding my concession pass.’

It can be a problem that you have to place the pass on a scanner to verify it. If the scanner fails, the holder only gets their free journey if they give up the pass, to be sent away to analyse the fault - assuming it is with the pass, yet the scanners often fail - a flimsy paper pass is issued only for a week, and it falls upon the passholder to obtain a new pass from their council.

An Autism Initiatives support worker had to demand (DEMAND - see page 86) gentler conduct from a driver about this situation, towards a passholder with a stammer who was not self-reliant or aware of the system. Clear good practice that she did. They gave up the pass, and weeks later it turned out this passholder had not retained any concept of contacting the council nor told his family he needed that, just accepted passively no longer having a pass.
When scanning began in 2008, the Traffic Commissioners experimented in some places with having drivers just seize any non-scanning pass and issue the temporary paper one whether the passenger liked it or not. This experience, where drivers could not contest that seizing the pass was theft, caused such complaints and distress that it was defeated and stopped within 3 days. From 2012 it popped up again, on Citylink coaches, and refusing to stop. It can also happen if the photo has been eroded by touching: only handle your pass by its edges. Passholders attending Edinburgh’s Number 6 began to report Citylink experiences of seizures happening and the new pass not arriving in time, leaving them without a pass without their consent. The passholder suffering a cost because of the system’s failure.

What if you are just beginning a holiday when this fault happens to you? or are taken ill before the opportunity to contact your council? or your work hours make it awkward to find a time to phone them in office hours? The unpredictable vulnerability done to them wrongs their safety in travelling, until the system stops all these seizures. - There is an actual piece of welfare rights work done right here!

‘I saw it done on a Highland route, to an old couple, not even at boarding when could grab the pass back, but in rural mid journey by an inspector. Just came to them and announced “I’m going to withdraw the card from you,” on grounds of unclear photograph. They were on their outward journey of a holiday and concerned for effect on their return journey. Citylink when complained to called this a “policy”, made not a word of admission of folks’ right to hold onto property, and indicated that passengers refusing to cooperate would be thrown off the coach, even in mid journey.’

Convenience?

Autism has a link to digestive health and more frequent urination. So we are one of the many population groups, also the elderly, who are affected by bus routes over 2 hours long being allowed without toilet stops. This affects all the long southward services from Edinburgh. Before the Borders railway reopened this put a practical barrier between the Borders and East-Central autism communities. The only way to cope (using their all-day tickets if no free pass) with 3 1/2 hours to Carlisle was to schedule a break at Galashiels or Hawick, losing travel time.

The stop at Abington services on the 3 hour Dumfries route would be the good practice model -
only would be, if it was always reliable. It’s not. Unchanged under 2 companies, some drivers do it, others either rush you or only allow a toilet stop if an assertive enough passenger makes the demand. An unconfident autistic passenger, who is not used to finding peer group back-up, might not demand.

Citylink’s northern routes standardly have toilets. But southward on 20 March 2011, a travel party were landed with an ordinary Stagecoach bus as used on Fife express routes, on a 3 1/2 hour service. Its driver was very good about it, full credit to him, when one asserted a loo need at Broxden, the park-and-ride coach stop on the edge of Perth, which had no loo at the time. It has since acquired one, we certainly had lobbied for it from this incident. A connecting coach’s driver refused use of his coach’s loo: “Absolutely not, no way, as soon as I’m loaded up I’m away.” That left the bushes, which meant climbing over a fence and squeezing under thorny vegetation, there was no other way out of sight without risking getting left behind. An older passenger with limited mobility would find this too hard to do, yet be even more likely to have the need.

Obtained from Citylink a whole 8 months later: "If there are no toilet facilities or they are not functioning properly, the driver will make stops at the request of passengers. If you are not comfortable asking the driver to stop during the journey, then you can explain when boarding that you may need a toilet stop and the driver should schedule a stop en route.” - Still none of this announced routinely to passengers, you have to suffer and write and chase before you get this.

Citylink had a long running problem with drivers jumping the Forth Bridge stop, seeming to find its existence an irritant. All pledges to raise driver awareness failed to shift it, because there was no consequence. Citylink needs to confirm to the travelling public a more autism aware attitude than had a driver in 2012 who ordered a more profoundly autistic boy who was agitated and screaming during a journey, and his father, to leave a coach at Harthill, contemptuously dismissing “my son’s autistic” repeated to him several times. It is doubtful he could have enforced it if physically defied, driving a public service vehicle with a duty to convey: but a victimised passenger can lack knowledge of that and feel too frightened to test it out.

**Cut our losses?**

There is danger in daily routine travel, that for 200 years we have been habituated never to question. The disaster that is done instantly to your life, your schedule, your finances, your
whole personal safety in unpredictable quantities, if a travel document gets lost or stolen. Your ticket or your passport, and identity cards in countries that have them as we nearly did.

Transport operators’ remedies for adults in this situation have become totally vague and noncommittal. We can no longer give our name and address to a bus driver, the out of date advice some of us heard from our parents. But we have the principle of disability discrimination now. The danger from losability of travel documents is a disability discrimination against autistics, because loss is a greater than equal chance for us. Our conditions’ link to dyspraxia and issues with “fine motor” skills, fine handling of small objects, attention deficit resulting in not noticing a loss. The distracted eye condition Irlen’s Syndrome, autism linked, seems likely to affect this too.

Then after the loss has happened we are worse off at the resulting emergency communication, at speaking to anyone, at trying to get a serious response without appearing to be a nutter, or if phoning is involved. But theft is not the victim’s fault, and loss of physical objects is a distressingly real human error we can’t live blamed for. CalMac ferries have stopped collecting tickets at end of crossing, as they used to in the 1990s: what did they used to do if a passenger had lost it during the journey?

‘Passport loss is now such a disaster, losing all the biometric identifiers built into the paper, that travel books advise to carry 2 photocopies of your passport on foreign travel. From which it is obvious that we are the affected minority and the medical case against requirements to carry travel tickets being allowed to exist. And getting rid of tickets and passports because of their greater than equal danger to us could have the effect of getting rid of them for everyone.’

Losable physical documents are inescapably contrary to the medical realities of all medical conditions causing increased likelihood to lose objects. Indecision or disagreement over what to replace them with, for trying to verify passengers, does not take this daily reality away from all spectrumites travelling further than walking distance from home.

Take it to the road
If public transport carries that fear, then try driving? Some aspies find it overloading of their senses and attention to learn to drive, but plenty are totally successful drivers as good as any NT. We found drivers and non-drivers equal in numbers. Able autism is no necessary barrier to driving. Instead some of us may have helpful specialised interests in cars and their care. But
the expense of acquiring and running a car will usually only be an option for the most successfully employed of aspies. It has its risks of loss: damaging an expensive car in an accident, and cars' ageing and decreasing reliability.

'My car is my safe place away from home.'

'Our local bus does not carry dogs so my best friend can't come with me.'

'I don't drive because the experience would be too stressful for me.'

Two respondents cited frustration that without a car there is limited access to hillwalking and rural areas.

Less heavyweight than a car but safer and more substantial than a motor bike, is a "microcar" or "quadracycle": a 4 wheeled light vehicle with a part-electric engine more like a bike's, but it can have a fascia fitted over it to look like a small car. They are more suited to rural than city driving. They have been popularised in France. Our driver licensing system has no separate provision for them and is confused by them. This has been a logically frustrating painful loss to an older aspie who owned an Aixam microcar, who got a lot of fulfilment from Highland mountain climbing away from sparse bus routes. To keep a licence meant passing a test in and for a different type of vehicle than the only type he wanted to own or drive: either learning motorcycling just for the test or passing in a full weight car.

'You could not expect to pass the test in a type of vehicle you'd never practised on. If they gave me a tractor or a bus and expected me to drive it on a test without any practice, then of course I would certainly fail! Before you take another test, you must make sure you've had practice in the right kind of vehicle: this is what driving schools are for.'

'Provided that I have good enough coordination and eyesight I should be allowed to drive, if not full size cars then smaller vehicles including innovative Continental vehicles I am prepared to accept a restricted licence which may exclude me from dual carriageways.'

Summary
Public transport has to be coped with in planned logical steps. Upsets to the plan are a frequent challenge to logical minded passengers, because in real life we can't meekly accept travel failures and missed connections, as bureaucratic minds expect us to. Driver licensing is not adaptable to personal solutions either. By having pigheadedly narrow rules around stopping
places and hailing, instead of allowing common sense, bus companies only endanger road safety. Circulating problems in the autism scene when they happen might lead to better outcomes.

Reflective questions

- When someone is more fearful than you to use a form of transport, how would you discuss its difficulties with them honestly and avoid causing either a paralysing hopelessness or overconfidence?

- When someone who you support has a serious transport complaint, and it gets a rubbish answer, do you make the effort to keep ever alert for further opportunities to press for the bad practice's ending? Do you find that burdensome as a caring duty?

- What autism services would it take to make transport a safe and reliable experience? Both for your local needs and for travel further afield?
Chapter 16  Holidays and Travel Experiences

It is well known that many people on the autism spectrum rely on familiarity and routine to make their lives comfortable as possible in what is an unpredictable world. Many spend their lives doing the same thing over and over again and this comfort zone whether it’s at home, work or leisure takes a lot of preparation to move out of.

Even so a holiday whether for a day or for a week is also vital to many on the spectrum who seek “a small break” from routine before looking forward to returning to it. Despite the obstacles travelling away from home poses, many autistic people very much have a desire and drive to see places for themselves and experience different cultures in a way you can only do by being there. It is also only natural for some people, who for instance has an interest in geography, to take an opportunity to travel somewhere different from the norm and the proper preparation has been made. Like all different people, the destinations and activities once there will vary.

'As someone who has focused special interests in geography and transportation, I have naturally had some interest in travel as a consequence. I can't say I'm someone who has travelled extensively, but I have been on a couple of big trips that are worth sharing as being a success.'

'These were both self-arranged tours by train on my own and the first of these was around Spain in 2002. It was a trip from city to city - Barcelona, Madrid, Seville etc., visiting the best known sights in these cities as well as football stadiums. My memories of the trip are actually somewhat hazy these days, compared to the other big train tour I did, I just mainly remember that Spain went well and smoothly in general.'

'The other big tour I have been on by train was around the United States in 2009. This one was I'd say more eventful than the Spanish one, with a few more (mostly social and interpersonal) lessons learned, but it was a trip I am still very much able to judge as a success. It was coast to coast, New York City to California and back.'

Some individuals like to prepare as long-term advanced as possible in terms of travel and accommodation to feel that all arrangements are in place as much as they can be.
The first big step is leaving your home to go on your holiday as you will be leaving for at least a day or not much less. A home is a safe haven for almost everyone and in autistic terms, many will set theirs up in a particular manner or shape to make it feel safe and comfortable. The feeling of leaving such a familiarity is a challenge and exiting may include a detailed check of switches (to see if there are turned off) and sometimes self-reassurance that all the planning made will fall into place once the journey begins.

Travel itself is the next hurdle particularly in terms of public transport when “strangers share a confined space” for mostly a prolonged period of time, depending on where you live or where your destination is, this can be an uncomfortable situation for many on the spectrum especially if travelling alone. This can be combatted with some “coping or positive distraction techniques” such as reading a book or listening to a portable audio device such as an mp3 player. Nothing can beat a bit of familiar company like friends or family.

The term “familiarity” becomes distant when anyone choses to go overseas - new language, new culture and of course new surroundings. As described earlier in the chapter a lot of preparation can go into this. However many on the spectrum have travelled all over the world, taking in different countries and cultures and the experience has been beneficial to them, despite initial stumbling blocks.

‘I booked a holiday in Montenegro to view my past life from a different perspective soon after my 75th birthday I had to leave Edinburgh at 4 am for a flight to Dubrovnik Upon arrival I boarded a coach for the 2 hour journey to Budva half way along Montenegro’s coastline I was awake enough to visit Budva’s Old Town then the following morning set off according to my plans to spend an afternoon setting out my thoughts about my past and future at a quiet cove called Drobni Pisejak I then walked most of the way back into Budva and took very many photographs of the spectacular coast as I walked along.

During the following days I visited Kotor, Herceg Novi, Ulcinj. Perast, Budva Starigrad and finally Petrovac to expose about 8 colour slide films and 8 colour print films It rained in Ulcinj and Perast at other times it was swelteringly hot for early October Perast is for all the world a row of Venetian churches and palaces alongside a Scottish sea loch! Herceg Novi has an outdoor theatre with commanding views over the inlet system called the Bay of Kotor whilst Budva overlooks a rocky island and Kotor is backed by lofty mountains Ulcinj is a run-down shabby seaside town. Petrovac has superb views from a cliff top.
I left Budva in a bucketing downpour and returned to Edinburgh on a fine evening. The cost all told was about £900.’

Although preparation is vital, not everyone discloses their autism diagnosis when making enquiries about their holidays as many feel it is a private matter and not necessary information if all self-preparation has already been made. However others look to use evidence of their diagnosis as a positive - e.g. ensuring the understanding of staff for someone who has autism arriving at a hotel in order to make things as comfortable as possible during their stay. There are many other examples of this.

‘The Norwegian Coastal Voyage sensibly accepted an advance explanation of need, from an aspie with a physical sensitivity for dressing in shorts, who checked that they would accept this for a 2 day journey along Norway’s High Arctic coast in May (2012) which is only early spring thaw time there. He had checked out the climate before making the enquiry. ’I can assure you your condition is not an issue for our ship, and note in regards to your condition will be added to your booking to notify the ship/crew so they can make sure everything runs smooth.’

Not all holiday and travel experiences have a positive affect, as many will feel exhausted by the mental strain of planning and emotional adjustment to somewhere “different”, whether at home or abroad when you take the consideration of changes of weather and above all - time.

America is so culturally prominent, and travel to it is so commonly encountered in present society, in conversation, as an experience and an idea, that any personal injustice around it is a social exclusion. It is basic to personal wellbeing in our society now, to have wellbeing when we encounter socially talk of other folks’ travels to the USA, chatted about as if it is casually easy. This was cited to the Best Value Questionnaire of the national autism strategy, in 2013: not yet with any known result.

There is a shocking human rights question around it. For a long time, American border control has been violating the oldest “free world” principle of all, innocent until proved guilty! by asking foreign visitors for histories of arrests, to judge them by, and asking “Have you ever been arrested or convicted…” as a single question.

After spending a certain period away from the “familiarity” of home and routine, this in itself takes preparation - although in certain experiences it also a “relief”. On the positive side of
things it is a growth experience having had a more comfortable after a testing time of “pushing yourself to the limit” and out of the comfort zone. On the negative side, for many on the spectrum, the reverted change isn’t always back to the old routine but rather preparation for a new one depending on how long you spend away from home and that in itself - meaning two mentally and emotionally draining experiences - can somewhat be the sole reason why many on the spectrum don’t want to take the risk of trying the holiday experience again.

‘I believe having the opportunity to go away somewhere on holiday, or for a break, can be great and can also be of much interest to those of us on the autism spectrum. If the place is unfamiliar however, you can often come home feeling more strained and less refreshed than when you left. All the organisation required for preparing to go, anticipating what you may need, the journey, plus the readjusting required for the new surroundings (and people) when you are there can be very exhausting. It takes significantly more mental resources and flexibility (socially and practically) being away from home than functioning amidst familiarity. This may mean holidays and travel to unfamiliar places are not are not an option for autistic people unless the challenges can be significantly reduced and/or largely borne for them, for example by somebody travelling with them.’

However as life has taught many people on the autistic spectrum, experiences - positive and negative - will always educate you. The education on preparation and adaption that will enhance future ideas of going somewhere again - for example having a shorter break, somewhere not too far away from home and routine but still different enough to enjoy your time away and feel confident enough to re-adapt to home life when it comes to an end.

Also on the positive front autism awareness is more wide-spread that it has ever been with training available to make organisations such as airports be prepared to accommodate those with individual needs. For example both Glasgow and Edinburgh airports have their own procedures to help people with “additional needs” and make sure as much as possible that their experience of travelling is a positive one.

_Carrie Doherty, station manager at Glasgow Airport:_

“At Glasgow when we receive a booking or request from somebody who has an autistic child or adult we recommend that they contact the airport direct to establish their individual need as these vary from person to person and the requirements may vary from airport to airport depending on the individual. At this point we would offer one of two choices. If the person has travelled before and are comfortable with the journey we would just send details of what is
required asking are they ok with noise, busy spaces, are they likely to run off, are there communicative etc. We would then tailor the assistance accordingly. This could range from taking them to the gate, arranging check in away from the main deck area, opening up a separate line at security purely for the family, being taken to a quiet gate etc. For those who have never used the service before we offer familiarisation tours for the family prior to their date of departure.

Having worked closely with autism groups, it has been brought to our attention that awareness of the service needs to be brought to the attention of the wider community. In order to do this we have prepared a booklet which has been sent to the printers.”

Kay Gillespie, Passenger Experience Leader at Edinburgh Airport:

“We are always looking at ways of improving the passenger experience. We offer an additional needs service for passengers on the autism spectrum. Our team will meet you on the arrival to the airport and will accompany you through check-in, security and then to the departure gate. They can also meet you on the return journey and assist you through immigration. They will do everything they can to make your journey as stress free as possible.”

A good holiday experience can set a traveller up for time to reflect, to appreciate beautiful surroundings and to achieve some tranquillity:

‘Montenegro is a tiny fragment of ex-Yugoslavia with 660,000 inhabitants I booked a holiday in Montenegro to view my past life from a different perspective soon after my 75th birthday I had to leave Edinburgh at 4 am for a flight to Dubrovnik. Upon arrival I boarded a coach for the 2 hour journey to Budva half way along Montenegro’s coastline I was awake enough to visit Budva’s Old Town then the following morning set off according to my plans to spend an afternoon setting out my thoughts about my past and future at a quiet cove called Drobni Pisejak. I then walked most of the way back into Budva and took very many photographs of the spectacular coast as I walked along.’

Reflective questions

(1) How do different people on the autistic spectrum prepare for the upcoming holiday and travel and what is the timescale?

(2) How do travel companies like the ones demonstrated at Glasgow and Edinburgh Airport make arrangements for people on the spectrum who require assistance?
(3) How do different people on the autistic spectrum re-adapt back into their “normal” routine and home life following holiday and travel experience - good or bad?

(4) To what extent do the adventures and experiences shared in this chapter illustrate the diversity of autism?
Chapter 17  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 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. As people grow older they may reflect on what their life has achieved and what kind of legacy they might leave behind:

‘So am I till the end of my days doomed to be a MISFIT in a SOCIETY BENT ON SELF INDULGENCE AND SOUL DESTRUCTION , desperately unfulfilled as I go on my lonely way amidst Scotland’s matchless scenery unable to share or pass on what I hold to be the now decomposing fruits of my self-createdness.’

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 fifteen - 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 maybe 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?
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