LIVING WITH ASPERGER'S SYNDROME

A service users' perspective

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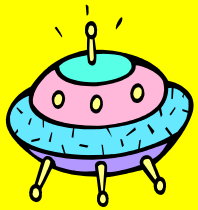
Imagine…



Imagine you have just landed on another planet and you didn't know the inhabitants, their language, their customs how they interact or how you should behave in their presence

Imagine trying to find your way in a foreign country with only jumbled signposts to follow and directions which you can only partially understand

Imagine not being able to talk, use your hands, use facial expressions or gestures and you had not been taught sign language

Imagine hearing ten television sets all at once and not being able to tune into any of them

For a person with Asperger's Syndrome, ordinary situations can feel just like this

Generation Gap

Experiences of people diagnosed later in life stress the importance of early diagnosis:

- There are many people who have been diagnosed late in life as there was no available diagnosis when younger
- I myself wasn't diagnosed until I was 20-years-old, by which time I had already been through school and was half-way through university
- By this time, no support services were available to me

Growing up with Undiagnosed Asperger's Syndrome

Teenage Years

- During adolescence, other teenagers thought I was gay because I didn't appear to have an interest in the opposite sex
- As a teenager, I lived a largely sheltered life, rarely mixing with others my age. The only time I really had any association with others was at school, rarely seeing people my age away from the confines of school rules and uniform
- As I feel I missed out on much when a teenager, my social skills didn't develop much and I didn't go through the process of social and emotional maturation that many go through during teenage years

Obtaining a Diagnosis

Problems that myself and my parents encountered when trying to obtain an Asperger's Syndrome diagnosis included:

- My GP at first hadn't heard of Asperger's Syndrome
- Two psychiatrists that I was subsequently referred to dismissed any idea that I may have the condition on the grounds that I was studying at university
- Eventually we had no choice but to go private to get a diagnosis

Which Path do I take?

Though diagnosis was a relief, after diagnosis, I felt my life was at the crossroads. I felt I had to find a path

I could walk my own path, but needed a path to walk on

Finding a Path

Not everything was easier for me since my diagnosis:

- Now that I knew more about my strengths and weaknesses, I had to ‘reinvent’ myself in some ways
- After graduation, I had real difficulty in finding employment
- The only way I could find into employment was through agencies, as I couldn’t manage the social skills required to get through job interviews

Lack of self-direction post-diagnosis

General lack of awareness of Asperger's Syndrome by different services meant:

- Difficulty in finding appropriate counselling
- Non-availability of supported employment scheme and lack of appropriate careers advice/support
- No access to supported independent living arrangements
- No help with managing transition to independent living or from university to work

Why Mountains have Base Camps

A base camp allows mountaineers to to take a much-needed break, review their progress before assessing the next part of the journey. Similarly, an Asperger's Syndrome diagnosis can enable one to review their life thus far, before assessing how to manage the next stage of their life, including aspects they may find difficult to negotiate

Who is hurt by inadequate support?

Lack of appropriate support doesn't only affect adults on the autistic spectrum themselves, but also affects:

- Their families, who may also worry about what happens when they are no longer able to support them
- Employers who miss out on potentially good employees
- The taxpayers who are paying for unnecessary crisis services

Issues faced by adults with Asperger's Sydrome

- Many adults with Asperger's Syndrome feel they have very little choice in terms of:
  - Where they can live
  - Where they can study
  - Where they can work
- Many have experienced difficulty in obtaining appropriate support in terms of:
  - Counselling
  - Access to supported living/housing
  - Support with studies and obtaining employment

Vulnerability?

Depending on their circumstances, adults with Asperger's Syndrome can be vulnerable in different ways:

- Young adults with Asperger's Syndrome who are part of a close-knit family unit may feel 'lost' or uncomfortable when having to step beyond it
- Other adults with Asperger's Syndrome who live alone or have no immediate family can be vulnerable to social isolation

Confusion for Services I

Asperger's Syndrome is often ignored as there is confusion as to 'where it fits' in terms of:

- Mental Health
- Learning Disability

Confusion for Services II

As a result, people with Asperger's Syndrome are moved between these services. In turn, this leads to:

- People with Asperger's Syndrome often remain undiagnosed without any clear assessment
- In some cases, people with Asperger's Syndrome can be misdiagnosed with other conditions (e.g. schizophrenia)

Where understanding is needed

Continual support and training is needed for staff working with people with Asperger's Syndrome is vital including:

- GP/Primary Care Team
- Teachers
- Children's/Adult Services
- Careers Advisers
- Potential employers
- Front-line services (e.g. Police, Law etc.)

Possible Support Suggestions

- Different support to that provided by current mental health/learning disability services is needed
- As many people with Asperger's Syndrome are very able, with informal rather than direct support they can lead independent lives
- Support is often of need to:
  - avoid social isolation,
  - manage change/transition effectively
  - reduce high levels of anxiety

Issues for Frontline Staff

Some issues for frontline staff from these areas of work to be aware of when dealing with a person with Autism/Asperger's Syndrome include:

- **Misunderstandings of social cues**
  - Many people with Autism/Asperger's Syndrome may have problems with eye-contact. Depending on the individual, eye-contact may be either absent, prolonged or intrusive
- **Social Naivety**
  - Some people with Autism/Asperger's Syndrome, concerned about what is the right thing to do may respond in a way that others find difficult to understand
  - May become over-compliant when interviewed and find themselves agreeing with suggestions that are untrue. They may not realise the consequences of this action for themselves and others

Supported Employment

To enable fairer access to employment for adults with Asperger's Syndrome in the north east, a supported employment service is needed:

- Every year so much is paid out keeping adults with Asperger's Syndrome on benefits, which could be put towards creating jobs that match their strengths and abilities
- This could help reduce much potential anxiety involved with job-hunting

Potential Employment Solutions I

Suggestions to help an Asperger's Syndrome candidate into a job include:

- To identify a suitable position for an employee, an aptitude test may be beneficial. This can also help identify the candidate's strengths/skills so they can be put to good use
- Employers could discuss with the candidate about any necessary arrangements to enable the candidate to perform their job better (e.g. a workspace not too close to colleagues)
- So that the candidate can get used to their place of work and their employer, a probationary/trial period may help. This would also help the candidate find out if a role is suitable or unsuitable for them

Potential Employment Solutions II

Suggestions to help an Asperger Syndrome employee keep a job and generally feel secure:

- Potential employers could be informed about Asperger's Syndrome and the difficulties the Asperger's Syndrome employee may experience
- To avoid anxiety, a timetabled routine with clear start and finish times and lunch break would be beneficial
- A 'buddy system' could be employed to avoid isolation and potential harassment/conflict. Access to a support worker would also be beneficial, who could also advise on issues such as Working Tax Credits, if the employee is eligible
- On-the-job training can be beneficial, as the Asperger's Syndrome employee may have difficulty applying college-based training to the workplace

No Quick-Fixes

As Asperger's Syndrome is a lifelong condition, it can't be 'fixed' or 'cured' short-term:

- Coping with a diagnosis of Asperger's Syndrome needs to be supported long-term
- Support is often needed into adulthood. For instance, a person with Asperger's Syndrome in his/her early twenties may experience when most NTs go through when teenagers
- People with Asperger's Syndrome must have access to appropriate support when needed, without cut-off points including:
  - Counselling
  - Support in education and finding employment
  - Social Groups

Accessibility of Benefits

Though Asperger's Syndrome is classified as a 'disability' by the Government, people with the condition still have difficulties in accessing benefits:

- Disability application pro forma clearly covers physical disabilities that require physical care, but there is little specific to mental, cognitive or developmental conditions (including Asperger's Syndrome)
- As many people with Asperger's Syndrome look physically able, it can be assumed that people with the condition don't fit the pro forma for disability benefits
- However, one of the aspects covered in the pro forma is that communication is a physical need, but is hidden under the term 'body dysfunctions'.

Accessibility of Benefits II

What service providers involved with people on the autistic spectrum must recognise is:

- Communication, verbal and non-verbal, is recognised by the Department of Work and Pensions as a ‘body dysfunction’. People on the autistic spectrum often have particular difficulty with non-verbal communication. It is important that local authorities recognise this
- Disability benefit forms ask about what support people need – it is often difficult to describe what many people on the autistic spectrum may need in relation to communication and general well-being
- Support people on the autistic spectrum require often applies to both home and work life. Such support that people on the autistic spectrum may benefit from includes counselling, therapy, access to a support worker/mentor as well as support in ordinary day-to-day communication at all times (e.g. mail, telephone, workplace communication etc.)

Housing and Accommodation

People diagnosed with Asperger's Syndrome can manage accommodation with the right support. But some current barriers to this are:

- For some people with Asperger's Syndrome, living away from home with strangers for the first time can be a big step
- As many people with Autism/Asperger's Syndrome are visibly seen as physically able, they may be expected to 'find their feet' without assistance
- For many people diagnosed with Asperger's Syndrome who live on their own on benefits, if they took a job would have to pay council tax and as a result may be worse off than being on benefits

Potential Housing Solutions

Some suggestions for local authorities/housing service providers to be aware of include:

- Looking at any adaptations that may need to be made to properties to accommodate people on the autistic spectrum in relation to
  - Sensory issues (e.g. lighting, sound insulation)
  - Environmental issues
  - Accessibility of public transport
- Providing appropriate support for helping people on the autistic spectrum come to terms with responsibilities relating to housing e.g.
  - Managing and paying household bills
  - General property maintenance if in private sector
  - Advice on which service providers to use (e.g. gasfitters, plumbers)

Public Transport

Adults with Autism and Asperger's Syndrome would benefit strongly from access to public transport:

- Can reduce so much potential stress of driving
- Some individuals on the autistic spectrum may benefit from a 'travelling buddy'
- To avoid confusion, it helps if public transport providers operate integrated services which require one pass for everything, to avoid confusion
- To enable this, local authorities could work with an individual with Autism/Asperger's Syndrome together with public transport providers

What is needed

Some recommendations drafted by the Autism External Reference Group (AERG) include:

- For local authorities to undertake audits to record the number of people on the autistic spectrum in the catchment area
- To appoint a team with responsibility to develop and provide services for adults on the autistic spectrum, to be jointly funded by local authorities and Primary Care Trusts
- To offer assessments to people on the autistic spectrum to identify their needs, so that personalised transition/care plans can be implemented

Long-Term Planning for Lifelong Condition

On the theme of Asperger's Syndrome being lifelong, services for those with the condition need to be planned long-term:

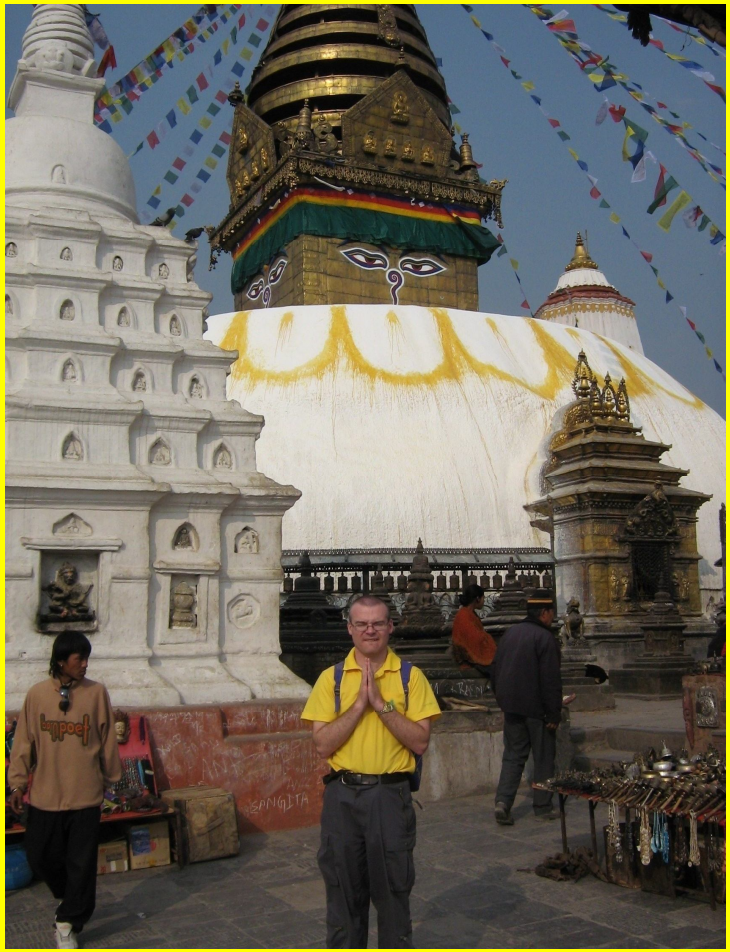
- To avoid providing services that are tried with the best of intentions but don't work, continuous consultation with the Asperger population is important
- To ensure that services meet the needs of Asperger population, their impact should be managed and evaluated over a long-term period
- Short-term funding is a risk, as it provides no scope for such effective evaluation of impact

Visions for an Autism/Asperger-friendly society

Visions that the AERG have for better services for adults on the autistic spectrum include:

- All adults with an autism spectrum disorder (ASD) are treated as equal citizens and are fully and appropriately supported to fulfil their potential and participate in society as much as they are able.
- All adults with an ASD are given the support they need to be empowered to take control of their lives, participate as much as they are able in society and pursue the lifestyle and relationships they choose
- All adults with an ASD have the opportunity to work, appropriate to their skills and impairments, and can access the support they need from benefits and tax credits.

A Triad for Understanding Asperger's Syndrome



- See through the lens of Asperger's Syndrome
- Acceptance of Asperger's Syndrome
- Awaken to Asperger's Syndrome

Tolerance of Asperger’s Syndrome

Opening up to people with Asperger’s Syndrome can enable effective tolerance, as knowing a person with Asperger’s Syndrome can change the way we are towards one another generally, as it can encourage inclusion. This way we can compensate and appreciate each others shortcomings through working together, rather than in isolation

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