



## **Response from the National Autistic Society Northern Ireland into Post Special Educational Needs Provision in Education, Employment and Training for those with Learning Disabilities**

### **Autism and the National Autistic Society Northern Ireland**

The National Autistic Society (NAS) Northern Ireland is the charity working throughout Northern Ireland for people affected by autism. In Northern Ireland we provide information, advice and support and campaign and lobby for lasting positive change for those affected by autism.

We have 12 NAS branches in Northern Ireland and an Adult parent support group, providing local sources of information and support. Many of our branches run social activities for children and young people with autism

### **NAS Northern Ireland delivers a number of services including:**

- Our **Family Seminar Training** Programme which provides parents and carers of school-age children, young people and adults with post-diagnostic information, advice and support
- Our Family support service providing individualise support and advice to parents and adults with autism
- Parent to parent confidential telephone support service, provided by trained parent volunteers who have personal experience of autism and want to support other parents
- Autism Helpline offering free confidential advice
- Education Advice line
- Welfare Rights Advice and support
- Our Teenscene Groups which provide social activities for teenagers
- Our social groups are for over 16's with high functioning autism or Aspergers syndrome and meet once a month for social activities.
- Training for the public and private sector including in the area of employment
- Social Skills training for adults with autism
- 1-1 education for adults with autism on relationships and health
- Short break activity weekends for adults with autism and their siblings (LEAPS Project Belfast Trust)
- Inter-capacity building service for adults in the Northern Trust

### **About Autism Spectrum Disorders<sup>1</sup>**

ASD is a lifelong developmental disability that affects how a person communicates with, and relates to, other people. It also affects how someone makes sense of the world around them. It is a spectrum condition, which means that while all people with an ASD share certain difficulties, their condition will affect them in different ways. It

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<sup>1</sup> The term Autism Spectrum Disorder is used throughout this document to refer to all people on the autism spectrum including classic autism (with an accompanying learning disability), Asperger Syndrome and high functioning autism.

affects around one in every 100 people. Some people with an ASD are able to live relatively independent lives but others may need a lifetime of specialist support.

Asperger syndrome is an ASD. People with Asperger syndrome are often of average or above average intelligence. They have fewer problems with speech but may still have difficulties with understanding and processing language.

Nearly 20,000 people in Northern Ireland have autism that's more than 1 in 100 in the population.

### **What proportion of people with autism has a learning disability?**

We do not know the exact number of people with autism and a learning disability but UK research would indicate that:

Between 44% - 52% of people with autism may have a learning disability.

Between 48% - 56% of people with autism do not have a learning disability.

Research findings on the proportion of people with autism spectrum disorders who also have learning disabilities (IQ less than 70) vary considerably as they are affected by the method of case finding and the sample size.

Fombonne et al (2011), in their research review of 14 prevalence studies that mentioned IQ, found a range of 30% to 85.3%, with a mean of 56.1%, of people **without** learning disabilities, p. 99.

For the purpose of this evidence we have included all people with an Autism Spectrum Disorder including Asperger syndrome because of the low numbers of adults with an Autism Spectrum Disorder in employment and also because of the lack of post educational support for all adults on the autism spectrum.

### **International Human Rights**

The United Nations Convention on the rights of the child (CRC) which was adopted by the General Assembly in 1989 came into force in September 1990 and is a widely ratified statement of children's rights. The United Nations Convention on the Rights of Persons with Disabilities (CRPD) was adopted by the United Nations Assembly in December 2006 and came into force in May 2008. Both these conventions have been ratified by the United Kingdom. Both the CRC and the CRPD are legally binding in international law and are pertinent to this enquiry as they enshrine in international law a comprehensive statement of rights for children and adults with disabilities.

### **Further Education**

The families who have been in touch with the National Autistic Society have raised a number of issues with regards to the provision and support that is being offered to young people with autism post school. Parents report that:

- Transitions planning varied with some parents and young people receiving good support and others receiving very little or nothing at all
- There is very little choice in terms of which courses their young person can access with some repeating the same course for a number of years "just for something to do"
- Colleges do not understand how to make "reasonable adjustments" to accommodate a young person with autism

- Young people with autism require travel training in order to prepare them to travel to college
- Young people with autism may require social skills training to equip them for college life
- Families have little or no support with regards to accessing work experience for their young person when at college or school
- Their young people are often vulnerable and parents worry about their safety and the level of supervision offered on some training courses
- The outcomes for people with autism and learning disabilities should be monitored to determine if the courses on offer are meeting their needs
- They feel that the school age for children with developmental delays should be extended further due to the fact that their development is delayed.
- Lifelong learning should be a concept that applies to people with autism and a learning disability and should be at the core of all support/ day services etc. that adults with autism avail of.

### **Case Study Alice**

Alice is 16 and has a diagnosis of Autism, dyspraxia and a learning disability she attended a primary school with support for 8 years, transferring to a learning support unit attached to a mainstream school for four years. In the last two years at the learning support unit they were preparing the young people for transitioning and helping them to make decisions about future work options or college courses. They were to attend the local college for one day a week and work experience for one day a week. The courses offered comprised of hairdressing/beauty, catering and childcare. Alice's mum thought these courses were totally unsuitable for her daughter who because of her learning disability and autism could not manipulate the tools and lacked the organisational ability for childcare and catering. Mum liked the idea of work experience but discovered that all parents of special needs children were expected to find their own work experience or the young person was to stay at home! Post 16 transitions was an extremely stressful time for Alice's parents. The transition team were "excellent, caring and compassionate" but admitted that choices for Alice were very limited given her vulnerability. Alice's parents viewed a number of options but discovered that a lot of the training courses offered by various organisations did not have the level of supervision needed to guarantee Alice's personal safety. In the end the parents opted for a post16 course at a special needs school which involved three days at a local college and work experience again to be sourced and arranged by the parents. Alice has settled in to the course well however for the first three days she did not have any food as no one showed Alice where to go and she wouldn't ask. Alice's parents are resigned to the view that their daughter will not get the skill set or opportunity to work post education and she is too able to attend day care.

Stephen is an 18 year old male with Asperger syndrome, dyslexia and dyspraxia he left an integrated secondary school when he was 16 and enrolled in a Media Studies level 1 course at a local further education college. With support he thoroughly enjoyed the course and was looking forward to going back to take the level 2 course in September. His parents were delighted that their son was doing a course in which he was interested and was making progress. However a few days before the course started he got a phone call to say that the course was oversubscribed and he no longer met the criteria. The young man did not communicate this information to his mother and he became "quite low" his mother felt his mood would get better once he recommenced college. When his parents became aware of the situation they contacted the college to see if they would reconsider and let him on the course. Instead he was offered the Princes Trust with the possibility of doing level 2 next year. The Princes Trust did give focus to the young person but it only lasted 3 months. The young man is now back in his bedroom, communicating and interacting with no one. He has no Social worker/key worker and no service. His mother is also worried as she is confused about whether she is still entitled to child benefits/child tax benefits.

## **Employment and adults with Autism**

In the current climate, finding employment is particularly challenging, especially for young people. However for those who face difficulties in the job market when times are good, today's environment compounds the struggle. For people with disabilities, in particular learning and developmental disabilities accessing the right support and opportunities to find sustainable employment is a greater challenge than ever.

People with autism face a particular set of challenges in achieving sustainable employment. The condition affects people's ability to communicate, meaning that some struggle to comprehend and respond to questions in interviews, and once in employment, some find it difficult to understand the unwritten rules of the workplace, to form relationships with colleagues and clients and to follow instructions. However many people with autism have an enormous amount to offer employers and with the right support, can develop and thrive in the workplace

- Unfortunately NAS research shows that just 15% of people with an Autism Spectrum Disorder (ASD) are in full time work

There is a lack of specialist support tailored to meet the particular needs of people with autism. Many adults with autism need support to develop skills for work, including access to social skills training. People also need support to navigate the recruitment process and employment support needs to continue once a person is in work. For example, a person with autism might be settled in their role, but a sudden change in the working environment, such as the departure of a colleague, or a new office layout, could cause considerable stress and anxiety and that person would then need access to specialist support. Currently, this specialist support is not widely available.

People with autism also face discrimination in the workplace. Employers regularly fail to make reasonable adjustments in the recruitment process and to jobs themselves. For example, people with autism can find hypothetical questions difficult to answer or often fail to make eye contact. This makes it hard for a person with an ASD to perform well in a conventional job interview.

There is very low awareness of the myriad of difficulties faced by people with ASD who want to work and the specialist and personalised assistance they will need to prepare them for employment.

- People with an ASD must be able to access ASD specific employment support.
- It is vital that employment support comes from people who are trained in ASDs and understand the particular barriers facing people with an ASD in the workplace.
- All professionals delivering employment support to people with an ASD must understand the communication barriers associated with an ASD. Without this knowledge it will not be possible to develop a clear understanding of an individual person's support needs and their ambitions for work.
- There needs to be clear advice given to employers around the reasonable adjustments that need to be made for people with an ASD.
- The Government needs to work with employers, making clear the benefits of employing people with an ASD.

### **Person centered planning**

When young people with autism and/or learning disabilities are transitioning into different phases of their life such as from school to further education work or day care the process employed should be based on person centred planning.

Person-centred planning is a process of life planning with individuals using the principles of inclusion, and a social model rather than a medical model. With a medical model, a person is seen as the passive receiver of services and their impairment as a problem; this often leads to segregation and places to live and work that are away from the community. A social model sees a person as being disabled by society. In this model, a person is proactive in the fight for equality and inclusion.

Person-centred planning has five key features:

- the person is at the centre of the planning process
- family and friends are partners in planning
- the plan shows what is important to a person now and for the future and what support they need
- the plan helps the person to be part of a community of their choosing and helps the community to welcome them
- The plan puts into action what a person wants for their life and keeps on listening - the plan remains 'live'.

### **Person-centred planning and people with autism**

Person-centred planning is based around the individual and is, therefore, ideal for people with autism and Asperger syndrome. When working with a person with autism or Asperger syndrome, planning tools may need to be adapted and terminology often needs to be changed so that it can be understood by the individual. It is essential that people's preferred ways of communicating are taken into account so that they can play a full part in the planning process. In Northern Ireland there is a lot of talk about person centered planning but in reality this very rarely happens and people are

directed towards existing services and expected to “fit in to them” rather than services being built around their needs, wants and their choices.

### **Personalisation and self-directed support**

In England there is an increasing move towards personalisation and self-directed support in the provision of services and assessment for adults accessing community and social care. Pitts (2009) defines personalisation as a system which enables everybody who needs support to have information, support and assistance at a time and in a way that is right for them. Where someone is entitled to social services funding to meet their care or support needs, this new way of working is referred to as self-directed support.

Self-directed support is person-centred but in addition the person knows how much money they are entitled to for their support and they have choice and control over how it is spent (Pitts, 2009). This money may be referred to as a personal budget, or, where more than one type of funding is involved, as an Individual Budget.

An excellent example of personalisation in practice is outlined in a book “personalisation in practice” by Suzie Franklin and tells of the story of her daughter Jennie and how she transitioned into adulthood using person centered planning and individualised budgets.

### **Case Study Jennie**

Jennie is a young woman with autism and a learning disability who has successfully made the transition from living at home to having her own flat bought through a co-ownership agreement with a housing association which gave Jennie a secure and stable home for the future. A circle of support comprised of family, friends and professionals came together to help support and contribute to Jennie’s future. The circle of support will be in place for when Jennie’s parents are no longer able to help care for her. With the use of individualised budgets and person centered planning Jennie now has a home, a team of support workers and a range of opportunities throughout the day that she chose based on what she likes to do. Jennie lives in her flat during the week and spends weekends with her mum or dad; she accesses the local community, attends a day center once a week and is getting to live the life she chose.

### **Access to Day Opportunities and Day Care**

Personalisation is not currently at the forefront of practice in Northern Ireland. Many of the families that the National Autistic Society Northern Ireland represents express fear and frustration as their young people leave the security of school and enter the world of Daycare and Day opportunities. They feel that they do not have proper information on available options including supported living, adult residential care, day opportunities or day care if needed. Parents and young people feel that they are extremely limited with regards to what they can transition on to. Parents and young people with autism have raised the following issues:

- Lack of choice with regards to what options are available to young people with autism. Services are not person centered but based on what is available locally
- Many Day Care centers are not suitable for people with autism who have sensory difficulties and behaviours that can be challenging. The National Autistic Society family support service supports a number of families who have no day care or day opportunities for their adult sons or daughters. Some of these families have seen their son or daughter “excluded” from day care and has had no option but to keep them at home.
- There are limited day opportunities for people with autism to access and some people would need more support to able to access the day opportunities available
- Young people with autism are in day care centers which are not stimulating or age appropriate and which the young person does not enjoy but there is nothing else available in that area
- Families have reported that they have been refused Direct Payments or told “there is no budget” so have not gone for them as they feel it is a waste of time.

### **Case Study Mark**

Mark is a 20 year old male who has a diagnosis of a severe learning disability and autism he has behaviours that challenge. Mark finished his schooling in the WEELB area after his 19<sup>th</sup> birthday. Day Care and Day Opportunities were unable to meet his needs because of his tendency to remove clothing and other behaviours. The family were offered direct payments in lieu of day care opportunities but were unable to avail of these as he has a younger brother who is 15 and has the same condition Marks 15 year old brother is out of school due to self harming and he cannot tolerate carers coming into the home. The family have been trying to secure a housing adaptation to accommodate both young people but to date a suitable adaptation has not been forthcoming.

The names of the case studies in this evidence have been changed but they are all current cases.

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