

Improving Lives: Autism



Support for those providing support

Speaker:

Les Neal – Operations Manager

An ordinary day...

Imagine you where in a foreign, noisy, crowded city at night, not understanding the language spoken, recognising only a few words but not really comprehending situations taking place around you, wanting to express a need for help but not being able.

This experience may begin to help you relate to what a child with autism feels on an ordinary day.

Some interesting facts...

- There are an estimated 120,000 school-aged children on the autism spectrum in England, the vast majority (73%) in mainstream schools.
 - 75% of children on the autistic spectrum of secondary school age say they have been bullied at school.
 - 22% of young people on the autistic spectrum who responded to a survey by the National Autistic Society said they had no friends at all. One in 10 said their friends were mainly adults. Half said they would like more friends.
 - Only 15% of autistic adults are in full-time paid work. 53% of people on the autistic spectrum say they want help to find work, but only 10% get the support to do so. 43% of those who have worked have left or lost a job because of their autism.
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Some interesting facts...

- 44% of people on the autistic spectrum responding to a survey by NAS said they stay at home because they are afraid of being abused or harassed – almost half (49%) said they have been abused by someone thought of as a friend.
 - 75% of parents in an NAS survey said their children on the autism spectrum had been labelled “naughty” or “strange”. 72% said that people avoid them, 74% said people make disapproving noises, and 87% said people stare.
 - More than one in four (28%) autistic people have been asked to leave a public place because of their autistic behaviour.
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Some interesting facts...

- More than 99% of the public said they have heard of autism – yet only 16% of autistic people and their families think the public have a good understanding of the condition and how it can affect behaviour.
 - More males than females are diagnosed with autism, with different studies putting the ratio anywhere between 2:1 and 16:1. But recent research suggests that the number is far more equal than previously thought; the problem is that professionals often don't understand the different ways autism can manifest in women and girls.
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Supporting Parents and Carers

Presenting issues:

Fears of being reported to social services because people confuse symptoms with neglect.

Being told it's their fault in some way or another, that they're not adequately parenting the child.

Difficulties in understanding their child's behaviours and the confusion that results from their inability to make sense of these behaviours.

Supporting Parents and Carers

Presenting issues:

The difficulty of obtaining and the alienating effect of ECHP assessments.

Support with understanding the benefits system, form filling, medical reviews & interviews.

Appropriate housing and demands on availability.

Lack of peer support for parents and carers.

Supporting Parents and Carers

Presenting issues:

Fear of bullying, gang initiation, CSE and the Criminal Justice System.

Reduced support from statutory bodies, (austerity).

Feelings of isolation, loneliness and exclusion.

Sleep deprivation.

Meltdowns.

Supporting Parents and Carers

Presenting issues:

How to access support around self harming and suicidal thoughts.

Inadequate transition plans from children to adult services.

Difficulties in obtaining a diagnosis.

Social media and the negative effects on children and adults.

Supporting Parents and Carers

Case study (37 year old mother:)

“The hardest part for me is how alone I feel as a parent.”

The hardest thing for me is how alone I feel as a parent. When I’m not being accused of bad parenting due to my daughters behaviour, I’m on my own trying to find resources. My daughter is in mainstream school and she sometimes acts aggressively towards other children, hitting or biting them. The teachers and some other parents have accused me and my husband of not being strong enough disciplinarians with her...

Supporting Parents and Carers

Case study (Derek 27 year old father:)

“Nothing about autism is easy.”

Nothing about autism is easy. You can embrace it; you can find coping mechanisms and you can find small ways to make daily life easier but that doesn't make autism easy. You can hold and rock and console your child but that doesn't change the fact that not having; “hamburger right now,” will put them in a meltdown.

Supporting Parents and Carers

Case study (Julie 29 year old mother:)

“And that’s just what Monday looks like.”

Everyday we stop our child from running away, manage meltdowns, avoid sights and sounds that overload his senses ... And that’s just what Monday looks like. We do all this while sleep deprived. Our child just doesn’t sleep very well so neither do we.

Supporting Parents and Carers

Case study (Marilyn 66 year old mother:)

“That was four decades ago and my son still lives at home.”

People don't understand that the stresses don't necessarily end on a child's 18th or 21st Birthday. I can't say the stress is any less now than it was when my son was three years old. That was four decades ago and my son is 46, unemployed and lives at home.

AUTISTIC SOCIETY GREATER MANCHESTER AREA



Vision statement



“We are a community organisation which offers support to people on the autistic spectrum. We enable personal and professional development and focus on unlocking potential, creating opportunities and giving our members a sense of personal freedom and choice”

A growing need...

- ASGMA was founded 50 years ago to support members, their parents and carers.
 - Funding changes and awareness of ASC mean the profile of the provision provided has changed dramatically.
 - Now supporting professional, clinical, educational and statutory bodies as well as parents and carers.
 - Provision of practical, social, emotional and legal support are now required.
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Our Work



- Social and leisure group activities
 - Parental and carer support (one to one and group)
 - An Information and Education Service
 - One-to-One support
 - Life skills coaching
 - Autism@Work
 - ASC Connect
 - HB Villages
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Questions?



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