



AsYouCan – Introduction to Autism

What is Autism?

When we say the word "Autism" many people will instantly think of "Special Needs" or "Disability" in general without ever really learning what autism is or understand what it is not.

Autism is, in and of itself, neither a physical or intellectual disability. It is a developmental disorder which means that people with autism develop differently, particularly in the areas of communication, interaction and sensory processing.



These differences can manifest themselves in a wide variety of traits, challenges and abilities.

We talk about autism as a "spectrum" because no two people are affected by the condition in exactly the same way as, they are affected to varying degrees, in varying ways. We sometimes hear people with autism, referred to having "Aspergers Syndrome", "PDD-NOS", "Social Communication Disorder" or other such labels, these are "forms" of autism or may describe a section of people on the Autism Spectrum, we will use the term "autism" throughout these documents to explain the spectrum as a whole.

We do not fully know what causes autism. I is a lifelong condition which individuals are born with. We know that it is a condition which can run through family lines and that approximately 1 in 100 of the Irish population are affected by the condition, with significantly more males affected than females. We also know many people with autism also have other additional needs such as an intellectual disability, dyslexia, dyspraxia or epilepsy.

Autism is an "invisible condition" in other words people with it do not look any different to the rest of the population. This can present challenges both in terms of diagnosing the condition and how people with it are treated by society. The general public can be quick to label people and cast assumptions based on an individual's behaviour. We like to use the analogy of outer space, when explaining autism to people:

"Imagine if you were put in a rocket tomorrow and flew into outer space, landing sometime later on a planet, unknown to you, inhabited by an alien population.

You wouldn't know the local rules, laws or customs. You wouldn't know how to engage or find common ground with the alien population. You would struggle to cope in day to day circumstances in alien schools, workplaces and the alien social scene.

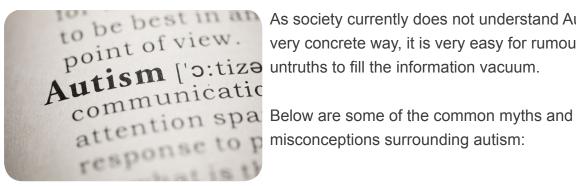
In order to cope, you try to observe and rationalise how the aliens behave. You look at situations, which cannot necessarily be easily defined, and yet you try and define them as "black" or "white" in an effort to comprehend what is going on around you and how to negotiate your way around it.



You construct a routine to try and stop anything which moves you outside this safe zone, you struggle to keep your cool around the local smells, textures and noises. Feeling so different, alone and afraid, you feel anxious and may even withdraw or opt out of socialising. Instead you might become used to your own company, you might develop fascinations or obsessions with specific subjects or find you are constantly amused by your own thoughts, sometimes becoming hyperactive and struggling with concentration."

With this in mind is vital that we all learn a little about autism, and consider our own experiences so that we can adapt for and support those living with Autism in our society.

Autism – Mythbusters



As society currently does not understand Autism in a very concrete way, it is very easy for rumour and

Autism is caused by

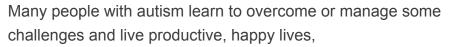
If you put the word "autism" into a search engine, you will find no shortage of claims to what is the cause, some may be serious research projects while many more will be ludicrous suggestions, with no grounding in science, such as "over-protective or under-attentive parents". While there are many theories, the prevailing theories all recognise that autism is not induced by the behaviours of others but has a biological basis of either genetics or environmental factors or a mixture of the two.

You can "get" Autism

People who do not have autism sometimes presume this is a condition you can develop or pick up from other people! It is not something you can develop in life, it is a lifelong condition which you are born with, nor is it something which you can "catch" from being around people with autism

People with Autism can be "cured"...

People with this condition cannot be "cured". They can be provided with many therapies, interventions and supports. These are aimed at helping the person to learn to communicate, to cope with their surroundings and to learn necessary living and social skills to help them integrate as far as possible in their daily lives.



fulfilling their personal potential, however autism is not something which goes away. There are many people who claim they can "cure" the condition but this has no scientific grounding.

Autism is an intellectual disability ...

It is not, in and of itself, an intellectual disability. Some people with the condition, may also have an intellectual disability, however it is important not to presume a person has an intellectual disability just because they communicate, think or behave in a different manner to you or others.

All people with Autism are geniuses ...

Likewise, not all people with autism are geniuses. Indeed, it is a relatively small percentage of those with the condition who have "savant" skills in a certain area or field. Just as in the general population, people with autism have different abilities and skills. Regardless of their intellect, some have skills in which they excel or display a particular talent for.



Children with Autism are just "bold children" / This guy is weird / He is just difficult....

The above are all variations of the same mistruth. We live in a very judgemental society where it is easy to look at someone who behaves differently and come to negative conclusions. Never judge someone until you have walked in their shoes, families and individuals with Autism often feel isolated as people cast judgements on certain behaviours. This can be because they cannot physically "see" a disability or feel they can question the reality of a condition in which they have no expertise

Key Challenges faced by people with Autism in day to day life

Communication

People on the autism spectrum vary greatly in their communication abilities and skills. There are those whose language skills are exceptional to the point of sounding aloof and even abrupt, to those with little or no verbal skills and everything in between. Communication is not just about speech. People with autism may have an impaired ability to understand language and abstract phrases. Many



will take a literal understanding of what is said. They may require a little longer than most to process an instruction or question. At times of stress their communication skills can be compromised.

Socialising



Socialising or interacting with other people can pose a challenge for people with autism. Many with the condition experience social anxiety finding day to day social situations highly challenging and stressful. In additon, the person with Autism may not know or understand social queues or etiquette which go with day to day social interaction e.g exchanging pleasantries or not being "over honest". Any or all of these challenges can form a further barrier to social interaction.

People with autism may find it more challenging to make friends or to interact socially with peers, in work or in school. As this is an invisible condition, difficulty with socialising, poor social skills and etiquette is often interpreted as odd or rude by those who do not understand. Bullying, isolation or labelling may ensue as a result.

Sensory

Sensory integration or experience for people with autism can pose many problems for them in their daily environment. Their individual senses may be over or under stimulated at any given time. As a result, many people with autism may have an unbearable dislike of particular smells, noises, textures, tastes or sights which can lead to physical reactions or behaviour. Similarly they may have certain textures or smells which they find soothing or calming.



This can cause a lot of distress and anxiety. It may mean that they avoid certain activities or locations because of an association with a particular sensory experience e.g a relative's house where there is a dog (barking) or the supermarket where the PA system may be in use.

If an individual with autism is exposed to a sensation which is particularly painful or upsetting for them – even in their own home – the physical effect can be so strong as to inhibit their ability to communicate the cause of their distress. At times it can be equally difficult for the person accompanying the person with autism to identify the cause of the distress.

Organisation

People with autism may struggle with organisational skills which can make day to day tasks like travelling on public transport or going about a job very stressful. Alternatively, a person may be very organised and ordered in everything they do, interference with their system can cause much stress.

Routine and "Black and White" Thinking

As you can imagine, people with autism can experience a lot of social anxiety. Many require routine and think in very definitive terms. This enables them to limit unknown and unfamiliar situations to manage their anxiety. Difficulty in reading social situations, an unexpected change to their schedule and sensory challenges in the environment can produce constant anxiety triggers.

"Stimming"

'Stimming' is a term used for repetitive stimulatory physical actions. When any of us become anxious we resort to little physical actions such as tapping a pen or drumming our fingers on the table. If we have been sitting for long periods of time we feel the need to change position

or get up and walk about. People with autism cope with their sensory needs in the same way but their physical actions may be much more pronounced and obvious to those around them. Some may need to jump, spin around, flap their hands or even emit a loud shout. These actions are, for the most part, involuntary and become more pronounced at times of stress. As children they have very little control over their 'stimming' but as they grow older they can learn to limit or control it to a certain extent. The greatest cause of distress in these situations is the public's reaction by staring or commenting on their behaviour.

Concentration

People with autism may find it difficult to stay focused on a given task, particularly if it is not something which interests them. This can lead to difficulties in getting things done on a day to day basis. They may also be highly focused when they are doing things they enjoy however, interrupting their enjoyment or their thought process of such an activity or subject may cause anxiety or irritation.

Anxiety and Stress



It is anxiety that lies beneath many of the challenges people with autism face and the more anxious a person becomes the more heightened other challenges such as sensory or communication may become. We all need a degree of stress in our lives however for people with autism whose anxiety levels are high at all times, it can take very little to push this to an unbearable level.

Behaviour

At times, people with autism find it difficult to communicate a frustration, manage a situation or cope in their sensory environment. When this happens, a person may display challenging or distressing behaviour or what some would term a "meltdown".

Public Perception

A key challenge for people with autism is the further disablement society can bring to them. Individuals can become frustrated at times because others, often well intentioned, can be patronising towards them or may not consider the individuals wishes. There can also be a tendency to stereotype or presume all people with Autism are the same – when in reality each person with autism is a person first, unique in terms of both abilities and challenges. Additionally they often feel judged by society, due to the invisible nature of their condition, others can be quick to draw assumptions about an individual with the condition and their

behaviour without knowing the full facts. People with autism have no choice but to live in a world not built for them and the lack of adaptability in society poses many challenges for them on a day to day basis.

What YOU can do

The power is in your hands! You now have an insight into some of the common challenges people with autism face and what you can do, as an interested and proactive organisation or person, to make life a little bit easier for individuals and their families. A little effort by you within your area of control can help making an autism friendly environment.

We ask and encourage you to make an "AslWill" Pledge such as one of those listed below. You can participate by simply taking a photo of your pledge written on our "AslWill" template and post it on Facebook or Twitter with #AslWill





We will highlight your commitment on our website and are delighted to support you in this undertaking at any stage. While we welcome any creative ideas for inclusivity here are some suggested pledges below:

AsIWill – Watch my language

We can be quick to use negative language when talking about people with autism or disabilities. We can do this in a very deliberate manner by using words like "retard", we can also be disparaging in our remarks about a person we know who has autism.

The other reality is, at times we don't know a person has autism but their behaviour is caused by the condition. We call people "weird", "odd", "freaks" etc. everyday but do we ever stop a think: "What damage am I causing with these words?" "Could the person have autism?" Maybe this can be your challenge!

AsIWill – See the person first

We can all fall into the habit of stereotyping, but really it achieves little and doesn't help you understand the person you are talking to, or empower the person as per their own abilities, challenges and potential.

Be armed with the facts but keep your mind open – make allowances where needed but don't expect to meet a walking definition of autism!

AsIWill – Make an effort to include

At times, there can be an assumption that people with autism don't want to be included. Indeed, at times they do need their own space and may avoid some activities or environments. However, they may like to have opportunities to interact and participate like anyone else.

We can be reluctant to invite someone with autism because we don't know how they will respond or perhaps feel that they will only say no – but just ask! If a person says no, once, twice or even a hundred times, one day they might be in a place to say yes.

Also, consider activities you know the person enjoys, this will help them socialise as it will be in a familiar setting in which they can relax.

Now bear in mind you don't always know who has autism – so be inclusive! During World Autism Month make a special effort to include, involve and invite those normally on the margins or who find it hard to participate.

AsIWill – Be sensory aware

Consider the sensory environment and things people with autism find difficult, try to be sensory friendly in your behaviour and environment.

AsIWill – Look at my communication skills

Are you clear in your language? Do people ever become confused with figures of speech or humour which you use? Do you use language in a way that is clear and concise? eg: Saying to a child 'Pull your socks up' when you really mean ' make an effort'. Consider this and the next time you see someone confused by what you are saying, employ what you have learned!



AsIWill – Spread the word

A big challenge for people with autism is the lack of awareness by the public. You have read this booklet, you have taken an interest.

Spread the message through conversation, social media and pass on your knowledge to at least one person!

