



Natalie Savage – Student Support & Wellbeing – 11.03.16

Libchat - Autism

What is Autism?

- Autism is a lifelong developmental condition. It is part of the autism spectrum – sometimes referred to as an Autistic Spectrum Disorder (ASD) or Autistic Spectrum Condition (ASC).

INSTITUTE FOR THE STUDY OF THE NEUROLOGICALLY TYPICAL

How Common Is It?

Tragically, as many as 9625 out of every 10,000 individuals may be neurotypical.

Are There Any Treatments For NT?

There is no known cure for Neurotypical Syndrome.

However, many NTs have learned to compensate for their disabilities and interact normally with autistic persons.

<http://isnt.autistics.org/index.html>

How common is it?

- Statistics from the National Autistic Society report that there are around 700,000 people in the UK on the autistic spectrum.
- At the University of Kent currently aware of 94 students on the Canterbury campus with Asperger's / Autism. Of these, 21 are registered with 'two or more impairments'.
- People with autism often have 'co-morbidities' of dyslexia and dyspraxia, attention deficit hyperactivity disorder (ADHD) or epilepsy as well as mental health diagnoses.
- 16 of those who disclosed to UCAS have not applied for an inclusive learning plan, or don't want one.
- Specialist mentoring support (currently 48 students), study skills support (14 students), ESA note taker / library assistant (10 students)

Diagnosis vs Identification

- Autism can be experienced by individuals in one of two ways. It can be explained as a different learning style, which when accommodated, could be thought of as an ASC, part of difference and neural diversity. If it's not accommodated, the individual may develop a disorder.
- The power of words – 'difference' and 'diversity' = colour/excitement; 'disorder' and 'deficit' = pathology.
- To access support (whether for PIP applications or for students, the DSA), individuals require a 'diagnosis'. The Diagnostic and Statistical Manual of Mental Disorders (DSM 5) is used by psychologists and psychiatrists when evaluating individuals for developmental disorders/conditions. Medical model - still uses the term ASD.
- Here at Kent, we prefer to refer to ASC although students can describe themselves as having an ASC, ASD, High Functioning Autism, Asperger Syndrome or just Autism.

'When autism is seen as damage'

Ally Grace – Respectfully Connected <http://respectfullyconnected.com/>

- I am pleased with who I am as an autistic individual, and with the brain that I have. I am genuinely glad to be me. But people actually regularly delight in telling me that I shouldn't feel that way; that this happiness is wrong. I am 'brain damaged' and 'have a neurological disorder', a 'condition', according to them. I should be angry that something made me this way, not happy to have the brain that I do. I should be, apparently, living each day with the constant belief that something is wrong with me.



Areas of difficulty – AKA 'Triad of Impairments'



- Autism is referred to as a 'spectrum' condition because although people with autism share three main areas of difficulty, their condition may affect them in very different ways. Some are able to lead relatively autonomous lives; others may require a lifetime of specialist support.
- Triad of impairments – difficulty with social communication, social interaction and social imagination.

Difficulty with social communication

- “For people with autistic spectrum conditions, ‘body language’ can appear just as foreign as if people were speaking ancient Greek’.
- Difficulties with both verbal and non-verbal language.
- Many have a very literal understanding of language.
- Difficulties understanding gestures, facial expressions or tones of voice.
- May not pick up on sarcasm or jokes.

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- Some use complex words/phrases, but may not be using them in a recognisable context.
- Others have difficulty knowing when to start or end a conversation.
- Some people have good language skills but may not appreciate the reciprocal nature of conversation.



Difficulty with social interaction

- “I’d always found it difficult to make small talk until I read that the aim of such conversations is merely to pass the time, and that it’s OK to drift from topic to topic without reaching any specific conclusions.”
- People with autism often have difficulty recognising or understanding other people’s emotions and feelings and expressing their own.
- They may not understand the norms of different social contexts: they may stand too close to another person or start what might be considered an inappropriate subject of conversation.

They may ...

- appear insensitive because they have not recognised how someone else is feeling
- prefer to spend more time alone than others
- not seek comfort from others in the assumed or expected way, or become withdrawn, disinterested or aloof
- appear to behave 'strangely' or not according to social expectations
- find other people unpredictable and confusing
- experience severe anxiety and over evaluate social interaction

Difficulty with social imagination

- “We have trouble working out what other people know. We have more difficulty guessing what other people are thinking.”
- Social imagination allows us to understand and predict other people’s behaviour, make sense of abstract ideas and to imagine situations outside our immediate daily routine. For autistic people it can be difficult to:
 - Understand and interpret other people’s thoughts, feelings and actions.
 - Predict what will happen next, or what could happen next.
 - Understand the concept of danger.
 - Prepare for change and plan for the future.
 - Cope in new or unfamiliar situations.

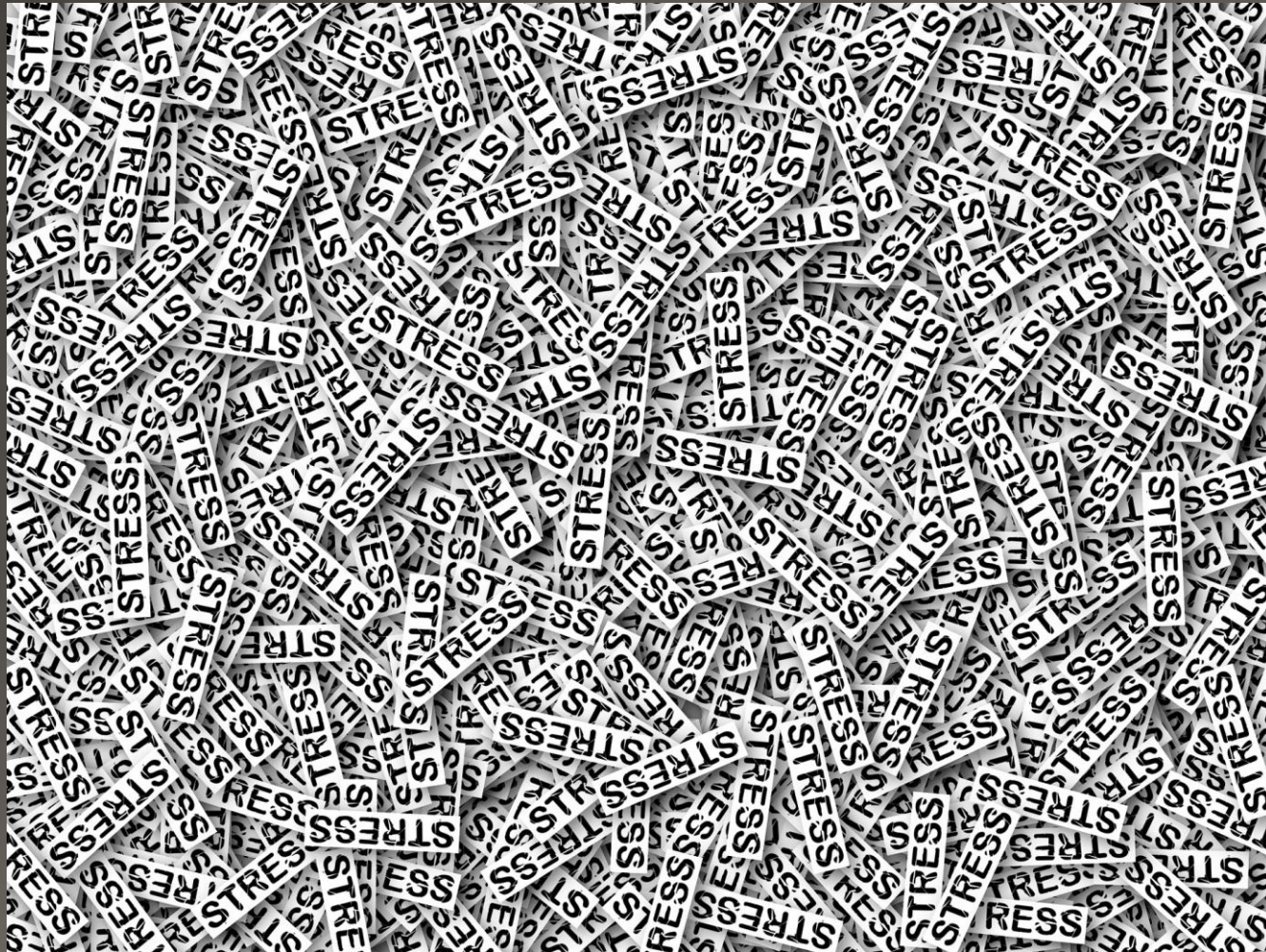
Imagination

- Difficulties with social imagination should not be confused with a lack of imagination. Many people with autism are very creative and may be, for example, accomplished artists, scientists, musicians, actors or writers. Famous people now considered to have had some form of autism include:
- Albert Einstein – difficulty with social interactions, experienced tactile sensitivity and language difficulties.
- Amadeus Mozart – reportedly had repeated facial expressions and experienced unintentional constant motion of hands and feet; hearing very sensitive as well as problems with social interaction.
- Sir Isaac Newton – quiet and not good at ‘small talk’. Extraordinarily focused on this work (forget to eat); relied strongly on routine.
- Charles Darwin – Avoided social interaction; demonstrated ritualistic behaviour and fixated on certain topics.
- Michelangelo – Single minded work routine, poor social and communication skills (described as being “preoccupied with his own private reality”).
- Others: Hans Christian Andersen, Andy Warhol, Emily Dickinson ...
- <http://autismmythbusters.com/general-public/famous-autistic-people/>

Routine, rules and rituals

- The world can seem an unpredictable and confusing place to people with autism who often prefer to have their own fixed, daily routine. It is often helpful to have routines they've created for themselves or which has been mutually agreed rather than one that has been imposed.
- Rules and rituals can also be important. It can be difficult for someone with autism to take a different approach to something once they have been taught the 'right' way to do it.
- Coping with change is challenging, but it is easier to cope if they are prepared in advance.

Sensory sensitivity



Sensitivity / Sensory Overload

- People with autism may experience some form of sensory sensitivity.
- Can affect one or more of the senses – sight, sound, smell, touch, taste, balance and body awareness.
- A person's senses can be intensified (hypersensitive) or under-sensitive (hyposensitive).
- Degree of difficulty varies from one individual to another and according to factors such as mood and levels of stress and stimuli.

Contd ...

- Some people find background sound unbearably loud or distracting which can cause stress and anxiety or even physical pain.
- People who are hyposensitive may not feel pain or extremes of temperature or have difficulty with spacial awareness.
- Hyposensitive body awareness also causes difficulties with fine motor tasks or not being aware of standing at an appropriate distance from other people.
- Some may rock, spin or flap their hands to stimulate sensation ('stimming') to help with balance or deal with stress.

Sensory Overload - a film by Alkurhah YouTube

<https://www.youtube.com/watch?v=K2P4Ed6G3gw>



'Fear, anxiety and Autistic Behaviour by Judy Endow

<http://ollibean.com/2015/12/05/fear-anxiety-and-autistic-behavior/>

- **"Try On a Tiny Bit of Autism:** Imagine your TV to be on all day and both the channel and the volume were entirely random and not in your control. The volume might be nothing or so loud as to be painful. You do not know when it will change. The TV is with you wherever you go. When you are working you are expected to relegate it to unimportant background noise even if it is so loud as to be painful. You never know if you will be interested in the TV show playing and if you are interested, chances are, the TV channel will change before the show is finished. When you are not actually supposed to be paying attention to this TV, like when you are at school or work, you are not able to turn it off.
- By now, you may be feeling a bit anxious. If this unpredictable experience occurred every day you might become fearful. Over time, your inability to control the sensory assault of the environment around you may become depressing. It would be understandable if you experience anxiety, fear or depression in response to this unpredictable TV. Now imagine this experience in all your sensory systems – not just auditory and not with only one auditory agent – the TV. This is often the autistic experience – but not always – because we can never predict."

Anxiety

- Experiencing high levels of anxiety is common. This can escalate to 'meltdowns' and trauma and result in complete withdrawal.
- Hyper sensory systems contribute to anxiety as well as social interaction.
- Catastrophising.



Highly focused interests

I DON'T AGREE THAT SPECIAL INTERESTS ARE 'RESTRICTED', 'FIXATED' OR 'ABNORMAL'. I DON'T FEEL 'PREOCCUPIED' BY THEM NOR DO I FEEL I DO THEM 'EXCESSIVELY'. COMPARED TO WHO? FOR ME, THEY ARE ENERGIZING, RESTORATIVE AND SERVE AN IMPORTANT FUNCTION IN ALLOWING MY BRAIN TO DO WHAT IT DOES BEST.

LEIA PRIME

- Many people with autism have intense interests, often from a very young age, which can change over time or be lifelong.
- A special interest may sometimes be unusual or less than mainstream but not necessarily so.

Women on the spectrum



- Female students need support to develop independence and strategies to reduce vulnerability.
- They also need to address self-image, self-esteem and confidence building.
- Because of the male gender bias in diagnosis, girls are less likely to be identified with autism, even when their symptoms are equally severe. This can lead to alternative diagnosis such as mental health problems.
- Approximately 1:4 female to male ratio (figures vary).

Support here at Kent

- Accommodation on campus for all three years of degree course.
- Assistance with resolving conflicts with flatmates, what to do when other students 'break the rules' (work with the Masters, Accommodation and Mentors).
- Sometimes self care issues – diet, hygiene (obsessive/careless), sleep issues, addiction to computer gaming.
- Isolation can be profound. We run weekly ASC Social Groups.
- Inclusive learning plans – for academic guidance e.g. student taking part in presentations and group work activities.
- People with autism face high risk of unemployment and we offer additional services from Careers and Employability.
- Society membership and religious affiliation can be very important. Students with autism may reject peer-led activities and seek special interest groups.

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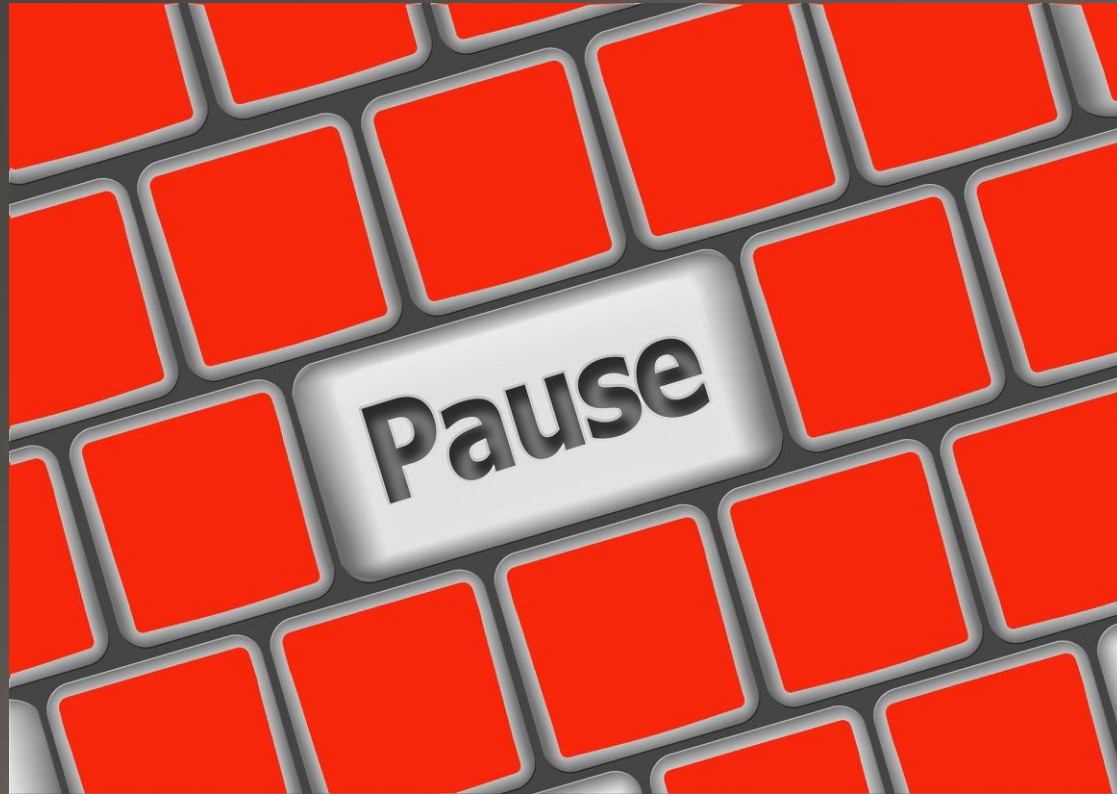
Last year we ran an Orientation Event three days before Arrivals Weekend to assist with student transition to university.

We are also able to refer students for a diagnostic assessment at the Tizard Centre (nine students per year).

Work with SU to address student concerns and raise awareness.



Time for a break?



Elensi Ludera by Luka – Emotive Piano Instrumental

<https://www.youtube.com/channel/UCGm24UFfvBkrHHanRN2BC1w>

- An original piano instrumental that I wrote as part of my album, Maya Mirën, which I created to thank people who helped me in many walks of life. It contains themes inspired by Ludovico Einaudi and Rick Wakeman and has a progressive feel to it. I wrote this late at night so it begins with a feeling of lulling into a dreamful sleep.



Using the Templeman Library - Student Comments



Working in the library

- “I tend to get most of my work done there. I tend to use the East Wing, - it is quieter.”
- “I often go when it is more peaceful; that is late at night when there are fewer people.”
- “There are not enough study spaces during the day.”
- “It is moderately noisy – but not too bad.”
- “There are not enough computers at peak times.”
- “I would like the ‘silence’ monitored and enforced more. Some students take no notice.”
- “I work in the computer room in the East Wing. I do not use the ‘new’ part. It is too noisy and too open. It is too crowded and there is a lot of wasted space.”
- “The light is too bright in the new part; I prefer the lower ceilings in the original building and the quiet corners.”

Likes

- “Overall I am very happy with it. I can usually find a space.”
- “I love it! (The new part that is) The café is also lovely.”
- “It’s okay. There are still places where you can read.”
- “I quite like it, I like the social areas.”
- “It's brilliant.”



Dislikes

- "I haven't used it."
- "It's too busy."
- "When I need help, I don't know who to ask."
- "Because I'm a Third Year, I can't ask for help 'cos people will think I'm stupid ... I've left it too late."
- "I don't work there, but I might do in the future."
- "The light is too bright in the new part; I prefer the lower ceilings in the original building and the quiet corners."
- "I don't like the open plan. People's noise is constantly disturbing. There are no private places to hold small group discussions. It is too crowded."
- "I liked the old study sections where it was closed in and quiet. The new sections are too open and too noisy. The sound carries easily, even small sounds carry and echo. There are no small silent/quiet areas to study. I don't study in the new part at all."

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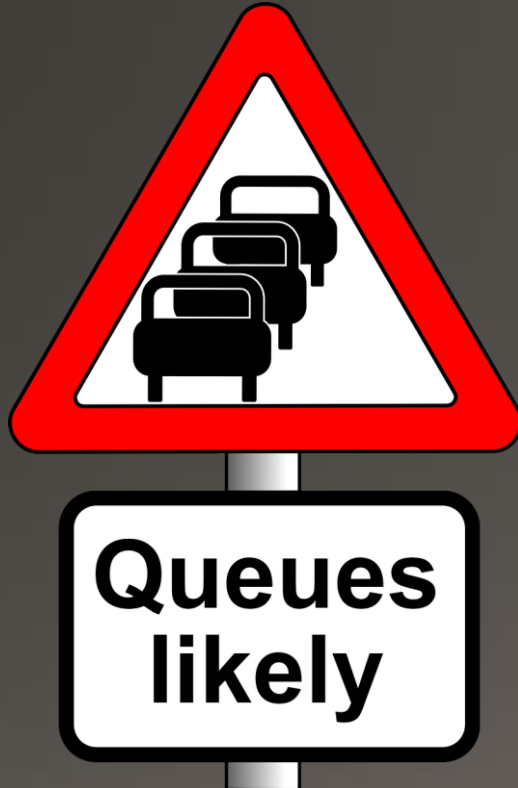
- “The water is too hot in the toilets.”
- “I hate it when people use the library to make phone calls ‘cos it’s quiet.”
- “Never go in there. I use the online resources though.”
- “Stuffy – not enough oxygen. Not enough computers.”
- “Stressful. Too exposed. Too much activity.”
- “Difficult to navigate – especially when you have to go around the building.”



Student comments/suggestions

- “More signage – I’m really afraid that I’ll go down to a dead end and then have to retrace my steps and look like an idiot.”
- “Separate 1:1 library tours that relate to my course only would be brilliant.”
- “Sometimes I’m told to speak to my Subject Librarian, but in my eyes, they’re too important to address because they might think my question is stupid.”
- “I’d really value practice sessions (task based) on how to navigate library facilities.”
- “Don’t make assumptions; either that I must know something or that I don’t.”
- “Do check understanding; if possible show me, not tell me.”
- “I’d like a video of library staff introducing themselves and saying what they do. This would take away a lot of the unknowns and make me less anxious.”

Student comments contd ...



- “Is there a way of letting students know the busiest/quietest times of day/term? They must have some clue about volume of students in there at various times so perhaps they could advise good times to visit and not have others waiting for staff and lots of people to contend with?”
- “Demonstrating empathy and patience would be great.”

Autism-friendly environment



- <https://www.youtube.com/watch?v=nJTI1dyL1zs>
- Professor Tony Attwood in conversation with Autism Care UK. Tony discusses Autism Friendly Environments, Transitions and what he would do to make society more Autism Aware.

Tips for dealing with students



- Some students do not like asking for help if they are surrounded by people. Maybe take them aside to a quieter space?
- Many are very anxious and would have tried to resolve their problem before asking for help. Listen to their needs and try to resolve their query in a direct way (perhaps write down information/directions).

More tips ...

- Some students may not be sure of what or how to ask for something. Do not bombard them with questions/answers in an attempt to be helpful. Give them time.
- Most importantly – mean what you say and say what you mean. Do not promise something that cannot be delivered.



Last words ...

- Don't make assumptions or judgements. If you pathologise someone, this is going to be a barrier to genuine connection and authenticity.
- Positive experiences will help the student to gain confidence and improve access.
- Negative experiences may mean that the student never returns.



Further Reading

References

The National Autistic Society 'What is autism?'

Autism autobiographies

- Grandin, Temple (1996) 'Thinking in Pictures' London Vintage
- Lawson, Wendy (2000) 'Life Behind Glass' Jessica Kingsley Publishers
- Jackson, Luke (2002) Freaks, Geeks & Asperger Syndrome, Jessica Kingsley Publishers
- Holliday Willey, Lianne (1999) Pretending to be normal – Living with Asperger's Syndrome. Jessica Kingsley Publishers

Text books

- Attwood, Tony (1998) Asperger's Syndrome. A guide for Parents and Professionals
- Wing, Lorna (1996) The Autistic Spectrum. Robinson.

- Web sites
- www.autism.org.uk
- www.autismasperger.net