Citation for published version


DOI

Link to record in KAR

https://kar.kent.ac.uk/62751/

Document Version

Presentation

Copyright & reuse
Content in the Kent Academic Repository is made available for research purposes. Unless otherwise stated all content is protected by copyright and in the absence of an open licence (eg Creative Commons), permissions for further reuse of content should be sought from the publisher, author or other copyright holder.

Versions of research
The version in the Kent Academic Repository may differ from the final published version. Users are advised to check http://kar.kent.ac.uk for the status of the paper. Users should always cite the published version of record.

Enquiries
For any further enquiries regarding the licence status of this document, please contact:
researchsupport@kent.ac.uk

If you believe this document infringes copyright then please contact the KAR admin team with the take-down information provided at http://kar.kent.ac.uk/contact.html
Autism training day
<table>
<thead>
<tr>
<th>Time</th>
<th>Session</th>
</tr>
</thead>
<tbody>
<tr>
<td>11.15 – 12.00</td>
<td>Introductions, followed by: Autism in an historical and social context</td>
</tr>
<tr>
<td>12.00 – 12.30</td>
<td>A different way of thinking</td>
</tr>
<tr>
<td>12.30 – 1.00</td>
<td>Interaction and communication</td>
</tr>
<tr>
<td>1.00 – 1.30</td>
<td>Lunch</td>
</tr>
<tr>
<td>1.30 – 2.00</td>
<td>Stress and anxiety</td>
</tr>
<tr>
<td>2.00 – 2.30</td>
<td>Supportive strategies</td>
</tr>
<tr>
<td>2.30 – 2.45</td>
<td>Open Q+A</td>
</tr>
</tbody>
</table>
Objectives for today

- What do you hope to gain from today?
Our objectives include:

- Providing you with information on autism, both from a theoretical perspective and from the viewpoint of people on the autism spectrum.
- Busting myths about autism and giving an overview of relevant supportive strategies.
Autism in a historical and social context
Activity

- Write down what you think autism is – or what you have heard autism is from other sources, such as the media.
- We will then gather feedback and discuss.
Autism – a history of the term

- Origins of the term – Bleuler, Kanner and Asperger.
- How was ‘autism’ defined before it was called ‘autism’?
- Changing psychiatric lens – Bettelheim, Rimland and Wing and Gould.
- Parent activism and charities.
- The neurodiversity movement and autistic self-advocacy.
Theory and practice

- What is autism? A contested terrain.
- Psychoanalysis
- Behaviourism
- Cognitivism and Neuroscience
- Sociology and Critical Disability Studies
- Autism from the ‘inside-out’ (Williams, 1996)
Current controversies – models of disability

- Models of disability:
- Medical: disability as something abnormal and pathological to be treated.
- Social: split between social barriers of disability and physical/mental ‘impairment’.
- Bio-psycho-social: taking into account biological, psychological and social aspects of disability.
- Some theorists also question the assumptions of ‘impairment’ and ‘normalcy’ (see Milton, 2012).
Have you heard about that Social Model of Shape Difference all the squares are talking about?

You mean the idea that all differences between shapes are imaginary?

Exactly. See that guy over there? According to this theory, he can't roll as well as we do because of our attitudes toward him!

Have you ever heard anything more ridiculous?

I guess when we are not looking, they bounce around like basketballs... Ha Ha Ha Ha!!

Oops, I thought I saw four right angles on that one. I must be hallucinating! Ha Ha Ha Ha Hal

Actually, that's not all what the social model is about. It's about how minority shapes are excluded from decision making roles, and therefore our needs are considered extraordinary while yours are seen as normal.

It's about power. The ways squares are silenced or ignored. How some shapes are subjected to treatments that would be considered abusive if they were done to circles.

So the social model is all about how squares are superior to other shapes. Can you believe he had the nerve to say that?

That's what I call rectangular logic... Ha Ha Ha Ha.

He probably bounced too high and hit his head on something! Ha Ha Ha Ha Ha Ha Ha Ha!!

Look at me! I've got corners! I'm invincible! Ha Ha Ha Ha Ha Ha!!

Please get off of me!

Square Talk

Asperger Square 8
‘Extremes of any combination come to be seen as 'psychiatric deviance'. In the argument presented here, where disorder begins is entirely down to social convention, and where one decides to draw the line across the spectrum.’ (Milton, 1999 - spectrum referring to the 'human spectrum of dispositional diversity').
Myth-busting

- Autism is not caused by vaccines, nor environmental toxins.
- Largely genetic, but also developmental environment plays a part.
- Autistic people do not lack empathy, emotion, humour, love.
- Autistic people do not all have unusually gifted talents.
- Autistic people cannot easily be sub-categorised – and indeed, perhaps this is best avoided.
- There is no ‘autism epidemic’, but changes have been due to changes in the way autism is recognised and diagnosed.
Current issues

- Impairment, deficit and the ‘spiky profile’. The diversity of needs.
- Prevalence rates and changing diagnostic criteria.
- Rates of diagnosis and the gender divide.
- Essential differences or social expectations?
- Passing, masking, and psycho-emotional disablism (Milton and Lyte, 2012).
References

- Asperger Square 8 blogsite (2014): http://4.bp.blogspot.com/_1vPB2M2lMil/SucK5Gau3TI/AAAAAAAACeQ/X8ANAC-forQ/s1600-h/social.model.png
A different way of thinking
Executive functioning

- Refers to the ability to maintain an appropriate problem-solving strategy in order to attain a future goal.

- Yet – there may be a difference within the way autistic executive processing operates, rather than an impairment or deficiency?
Central coherence and monotropism

- Refers to problems with processing overall contextual meanings, whilst simultaneously having advantages in processing details or parts of an overall context.

- Yet – many autistic people are able to process gist meaning and whole pictures.

- Monotropism and the interest model of autism (Murray et al. 2005).
Conformity and reputation management
Sensory perceptions

- Sensory integration and fragmentation.
- Hypo and hyper sensitivity.
- Context and motivation.
- Stressful stimuli.
- Stress, arousal and sensory overload – ‘meltdown’ and ‘shutdown’.
A different way of perceiving

- Synesthesia.
- “Aren’t all autistic people visual thinkers?”. Pattern thinking and Hyperlexia.
- Monotropism and the ‘attention spotlight’.
Enhanced sensory perceptions?

- The block design and embedded figure tests.

(a) Types of block available for making the pattern

(b)
Non-verbal intelligence

‘Non-verbal’ intelligence tests (Dawson et al., 2007)
How many senses does someone have?

What would ‘hyper’ and ‘hypo’ sensitivity in these senses be like?

What may help someone with such sensitivities?
Interaction and communication
Theory of mind

- The ability to empathise with others and imagine their thoughts and feelings, in order to comprehend and predict the behaviour of others (also called ‘mind-reading’ and ‘mentalising’).
The double empathy problem

- A case of mutual incomprehension?

- Rather than seeing the breakdown in interaction between autistic and non-autistic people as solely located in the mind of the autistic person. The theory of the double empathy problem sees it as largely due to the differing perspectives of those attempting to interact with one another.
Communication

Do...

- Adapt you own communication to suit the autistic person’s communication preferences.
- Use visual aids to support understanding if appropriate.
- Use concrete, specific and concise language.
- Be consistent.
- Allow time to process information.
- Be honest but tactful/respectful.
- Recognise opinions as such and that they may not agree with yours.

Don’t...

- Make assumptions about understanding based on use of expressive language.
- Dominate the conversation.
- Rely on non-verbal cues.
12.30 – 1.30  Lunch
Stress and anxiety
Introduction

- An exploration of factors that influence the levels of stress experienced by autistic people, and how this can produce a negative worsening cycle.
- How continuing high levels of stress and alienation can lead to mental ill-health.
- Finally concluding by looking at what can be done to reverse the negative spiral of stress that can blight the lives of autistic people.
Autistic dispositions

- As with the rest of the population – great deal of diversity in personality and temperament.
- Often with differing responses to stressful experiences when encountered.
- The ‘fight or flight’ response – ‘meltdowns’ and ‘shutdowns’.
Meltdown

- The ‘meltdown’ response and misunderstandings of it.
- ‘Challenging behaviour’.
- No choice in the matter.
- Non-autistic people meltdown too – e.g. road rage.
Noticing the less obvious - such as more passive natured autistic people and the 'shutdown' response.

Characterised by withdrawal.

Often unable to think clearly or to express oneself at all.

Again – no choice in the matter.
Shutdowns that are infused with emotional content and/or confusion can lead to a panic attack response.

This can be characterised by hyperventilating, and in a worst case scenario – passing out unconscious.
Once in such an overloaded state, confusion reigns and communication becomes largely impossible.

Do everything you can to reduce the stress in order to help.

Do not ask ‘are you alright?’ – as one blatantly is not!

I am not okay
Forms of stressful experience – information overload

- Multi-tasking, integrating information, and fragmentation.
- Interruptions to the ‘attention spot light’.
Mutual incomprehension (the double empathy problem)

- “95% of people don’t understand me”.
- “Friends are overwhelming”.
- “Adults never leave me alone”.
- “Adults don’t stop bullying me”.

Quotes taken from Jones et al. (2012).
Forms of stressful experience – emotional overload

- How others see you and how you see yourself. Emotional disjuncturc and ‘identity crisis’.
- ‘Exposure anxiety’ (Williams, 1996).
Social stigma

- The denigration of difference (Tajfel and Turner, 1979).
- ‘In’ and ‘out’ groups, stigma and discrimination.
Living with almost constant stress and social disjuncture, can be even more highly damaging when unrecognised.

- Alienation and isolation, withdrawal from society.
- Mental ill-health – from social anxiety issues to depression and catatonia.
- Remember – the outward manifestation of stress may be a lack of expression too.
Key points in reducing stress

- Acceptance of the autistic way of being, work with the autistic person and not against their autism.
- Watch out for ‘triggers’ in the environment (although sometimes these cannot be avoided – e.g. the dreaded fire alarm!).
- Explore interests and fascinations together.
- Having strong rapport and building mutually fulfilling and trusting relationships.
- Encourage autistic companionship.
- Encourage understanding of non-autistic people and culture, rather than teaching how to poorly mimic what one is not.
- ‘Low arousal’ is not ‘no arousal’ – many sensory experiences are fun!
References

Supportive strategies
‘People need to get over the idea that the 'neuro typical way is the right way and any other way is wrong. The AS way is just as valid, in fact better in some respects. We should be accepted in our own right, and the emphasis should be on educating NT's not to be so discriminatory, and to get over the absurd and offensive idea that they are better than anyone else. People with AS don't need to be cured, or trained how to be 'normal'. It's the 'normal' people who need to learn that, contrary to what they think, they are not the pinnacle of God's creation and there is, in fact, a lot they could learn from Aspies. They need to be taught not to be prejudiced and discriminatory, and to accept and accommodate us for who we are’ (ASPECT)
Many pitfalls
Three main ethical questions to ask:
- What is one trying to achieve?
- Why?
- Are there issues regarding these purposes, or the means by which one tries to achieve them?

Applied Behavioural Analysis and criticisms
‘Social skills’ and mutual respect / understanding
Sensory aides and the low-arousal approach
Intensive interaction and the work of Phoebe Caldwell
Being person-centred in approach and taking into account context
Introduction to SPELL framework

- Developed by NAS since 1964
  - A framework for thinking about and responding to autism
  - Ethical and inclusive
  - Overall aim: reduce stress and anxiety - aid mutual understanding and communication
- Goal - a more ‘autism friendly’ world
### SPELL framework: Very brief summary for mentors

<table>
<thead>
<tr>
<th>What?</th>
<th>Structure</th>
<th>Positive approaches and expectations</th>
<th>Empathy</th>
<th>Low arousal</th>
<th>Links</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>-Reducing anxiety through increased predictability</td>
<td>-Play to strengths -Assume ‘can do’ -but with help</td>
<td>Mutual understanding of perspective of others</td>
<td>-Recognise stress caused by sensory differences -Confrontation</td>
<td>-Promote consistency -Promote involvement</td>
</tr>
<tr>
<td>Underlying Difficulties?</td>
<td>-Organising, sequencing and planning – self monitoring</td>
<td>-Uneven skill development -Low or imposed expectations</td>
<td>-Mutual understanding / misunderstanding of other minds -Judgement of social situations -Literal interpretation</td>
<td>-Sensory processing -Stress -High anxiety</td>
<td>-Uneven processing of information -Detail v bigger picture -Response to change</td>
</tr>
<tr>
<td>Some examples</td>
<td>-Written or pictorial timetables/instructions/Diaries -Clear sequencing</td>
<td>-Positive /direct clear language -Use strengths and interests as motivators and to build confidence</td>
<td>-Reflection – Discussion -Pictorial aids -‘Social stories’ -Keep promises</td>
<td>-Audit sensory environment -Reduce noise/clutter -Reduce confrontation</td>
<td>-Inclusive meetings -Access to ‘mainstream’ facilities -Consistent communication</td>
</tr>
</tbody>
</table>
The starting point for PCT is the idiosyncratic ways in which people make sense of the world and how this influences their actions.

PCT attempts to approach issues through the viewpoint of the individual experiencing them, rather than fitting them into preconceived models.

Rather than seeing any interpretation as ‘correct’, one should look pragmatically at how useful such a framing is to one’s purposes.
Mental health and suicidal thoughts

- Mental health is a fluctuating state, dependent on various factors (Samaritans 2006).
- People on the autism spectrum are particularly vulnerable to mental health problems (Tantam & Prestwood 1999).
- It is important to feel comfortable having exploratory discussions with people who express despair or suicidal thoughts.
- The majority of people who express suicidal thoughts are unlikely to carry through their thoughts to action, but you must take it seriously when somebody expresses despair or suicidal ideation (Samaritans 2005).
- For advice or support you (and your mentee) can contact:
  - Local mental health crisis services: 0800 731 2864
  - Samaritans: 08457 909 090
Supporting families and advocacy

- Different forms of advocacy
- Charity advice and support
- Legal entitlements to supports and benefits
- Marguerite Haye


Any final questions?

- Is there anything you would like to ask about?