Autism Spectrum Disorder :

NEGOTIATING PUBLIC SPACES

Who Am I

-Qualified Youth & Community Worker, Diploma in Community Development, Degree in Social Science, Masters in Social Policy, Post Grad Cert in Teaching and Learning in Higher Ed.

-Lecturer in Autism Studies

- Part of the team that developed Autism Studies at UCC

-Specialize in working with people on the spectrum (and their families) individually and in groups

-Ten years experience of working with people with ASD

Books

- Living with Asperger Syndrome and Autism in Ireland (Stuart Neilson, Diarmuid Heffernan)

- Sensory Issues for Adults with Autism Spectrum Disorders (Diarmuid Heffernan)

What is ASC

- Is a partnership between Kirsten Hurley and I, includes people with ASD as peer mentors

- Its focus includes:

- Positive social interactions

- People with ASD can and should learn from each other

ASC

Structure of this Presentation

- What is ASD?
- This presentation uses my own research interviews
- School as a first public space: Expectations and social pressures
- Bullying
- Sensory differences
- Virtual Spaces
- Home and the Family
- Controlling the Home

Contact Details

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*Most of the literature on
Autism Spectrum Disorders (ASDs)
is written from the perspective
of 'experts'
(mainly in clinical professions)
<u>who do not have ASD.</u>*

What is ASD?

- ASD stands for *Autism Spectrum Disorder*

- Relatively new term (May 2013 – DSM 5)

- ASD now covers Asperger's syndrome (also known as AS) and 'classic' autism

- 3 levels of severity

So what is autism?

- Autism (and the other ASDs) is a neuro-developmental condition

- It is present from early childhood (even if it is not diagnosed until adulthood!)

- Autism is clinically defined by impairments – often referred to as 'the triad' (now the Dyad-we will discuss this more presently))

And what about Asperger's?

- Asperger syndrome (AS) is clinically differentiated from autism through lack of language and cognitive delay

- Asperger Syndrome is now considered to be an Autism Spectrum Disorder (ASD)

- Some people with AS claim it as part of their identity and do not see it as a 'disorder' at all

A bit of history…

▶ Leo Kanner and Hans Asperger both described what we now call ASD in the 1940s

▶ Autism was first included in the DSM III in 1980

▶ Lorna Wing coined the term Asperger's syndrome in 1981 - leading to the inclusion of AS in the DSM 4 in 1994

SO WHAT CAUSES ASD?

MYTHS, THEORIES AND 'FACTS'

- MMR vaccine (Dr Andrew Wakefield)?

- Refrigerator mothers? (Parentectomy)

- Environmental factors?

- Genetics?

- Prenatal environment?

- An adaptation to the technological age we now live in? (Baron-Cohen, 2001)

The Triad of Impairments

Impairments in Social Interaction

-aloofness, not understanding social cues, lack of desire to communicate with others, difficulty with social imagination, difficulties with body language

Impairments in Communication

- verbal and non-verbal language problems, lack of recipriocal conversation, literalness

Impairment in Imagination (flexibilty in thought and behaviour)

- difficulties with imaginative play, lack of understanding of others' perspectives, may have set routines, or limited interests, may have physical streotyped behaviour

Triad to Dyad (DSM 5)

Social Interaction

Communication

Repetitive Interests, Behaviours and Activities

Social Communication

RIBA & sensory issues
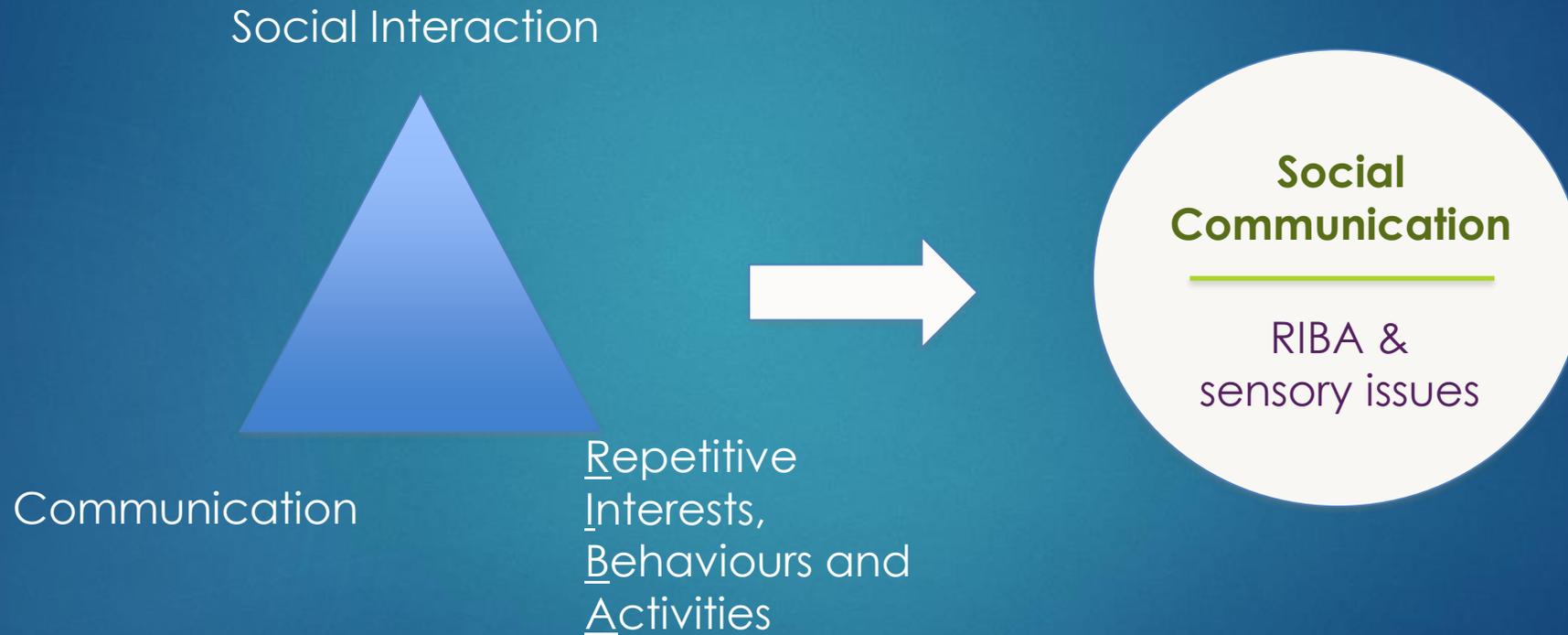
Social Communication

People with ASD may have difficulty with…

▶ relating to other people (understanding their thoughts, emotions and motivations)

▶ using verbal and nonverbal communication (gestures, body language, speech)

▶ adjusting their behaviour to suit the social context

RIBA and sensory issues

People with ASD may have difficulty with…

▶ Some environments that 'seem fine' to everyone else

▶ Changing topic or task easily

▶ Regulating time spent on interest of importance to them

Impaired Executive Function

Executive function is what allows us to plan, organise and sequence. It also helps us to control automatic or what may be deemed inappropriate verbal or physical actions.

Executive function also means being able to adjust to something unexpected happening, multi-task, or pay attention to someone talking to us even if there is lots of background activity.

Girls *with* **ASD**

- are often not diagnosed!

- present differently to their male counterparts

- struggle with social interactions (especially in large groups)

- can be very vulnerable and naïve
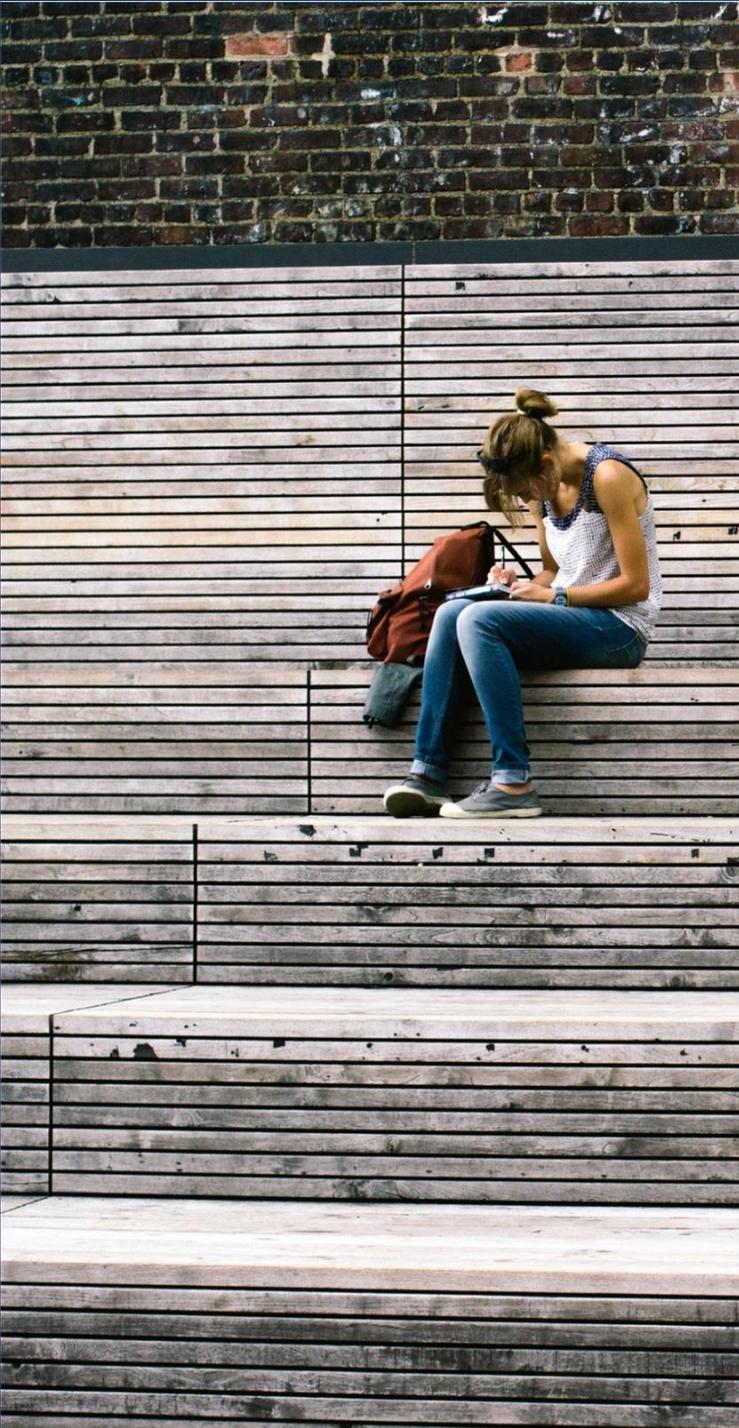
ASD and Public Spaces

- So what does all of this mean for people with ASD in public spaces?

People with ASD: Breaking some Stereotypes

- (Muller et al, 2008:187) "The characterisation of individuals with ASDs as socially aloof, deliberately self isolating, affectively flat, and lacking consciousness of their social skills deficits" was not the case and in fact the study found that people with ASDs were often the opposite of the "culturally reinforced stereotypes about ASDs" (Ibid:187).

ASD and School

▶ The school setting provides the first opportunity for most people with ASD to interact at length in and with a public space.

▶ The social world is filled with potential sensory stimulants for those with AS: "There are a million triggers lurking everywhere, waiting to set us off, steal our peace and sabotage our calm" (Simone, 2010: 35)

▶ The expectations of sameness and 'normality' are often difficult for people with ASD to abide by, not only because of the manifestations of their ASD but also because they often don't understand the expectations in the first place

ASD and Bullying

- Studies have shown that up to two in five people with ASDs have suffered bullying or peer victimisation (Batten et al, 2006) while this figure jumps to 90 percent of those with AS (Little, 2001, 2002, Balfe, Chen and Tantam, 2005).

- "major cause of social avoidance and distress" (Tantam, 2009: 155)

- For interviewee G his sense of being different led to his isolation in school: "when I was being bullied obviously my behaviour that would have been drastically different to everyone else around me.. I came across as being odd, as being different and I was picked out for that and it was very stressful at the time".

Interviewees experiences

- Interviewee E was also victimised at school but found a way of using the rules of the school to try and disappear into the system: "Mostly it was horrible I didn't get on terribly well with other people at school, I was bullied a lot but over the course of time I found way's that..if I followed the rules and I tried to be inconspicuous then mostly I can get through my life without trouble but there was a lot of bullying".

- "the worse it got at school the more relief I got at home, the more normality would be associated with being at home. So school left me in a position where the only time I could be normal was when I was at home. I reached a point where I decided that socialisation and public life were not worth it to me compared to my own sanity and normality and comfort". (Interviewee A)

School and its Repercussions

- "I still have to live with it..the name calling in the past it was always stuck in my head and it stuck in my body and it always kind of crops up and it upsets me like I feel down and worthless". (Interviewee C)

School and its Repercussions

► "When you are very uncomfortable for three years in a certain kind of environment that environment will always bring that uncomfortableness with it...and you see echoes of that environment in other environments" (Interviewee A focus Group)

► "It would be from the bullying I got I was worried afterwards that everybody was going to pretty much reject me the moment I tried to approach them so I have never tried to reach out for friends, when I tried to do that before I was being picked on so I waited for people to approach me and if they didn't approach me then that was it I wasn't going to be making any friends" (Interviewee G).

Initiating Conversations in Public Spaces

- **Interviewee F** "My favourite terrible conversation starter is 'So.. The weather'
- **Interviewee A** "They think you are mocking them.
- **Interviewee E** "That happens to me. I try to do the expectation and they say 'are you taking the piss?'
- Understanding expectations, As interviewee E states:
- "I think I know what they are but I get them wrong if I try to do them so I think I don't understand how they work, I try and make small talk about the newspaper or the weather but I always seem to get it wrong".
- Interviewee B elucidates this view: "I don't as in I don't know what people's expectations are most of the time".

Learning to fit in

- "Resourceful-if not representative-AS authors describe having learned to fit in through extensive, life long study of 'neurotypical' 'natives'. They have discovered for example which autism associated behaviours to suppress (e.g. echoing others speech or walking on tip toes) and which 'neurotypical' behaviours to mimic (e.g. smiling or making eye contact in order to present a more or less acceptable front" (Davidson and Henderson, 2010: 156).

- This is felt by many as a denial of their own identity:

- "People generally aren't bothered about other things around them so if you could-it's kind of ahm-you feel you are coming short in society if you aren't presenting as little interesting or attention drawing things as possible". (interviewee A)

Sensory Issues in Public Spaces

► Interviewee A talks about his experiences of heightened senses in public spaces:

► "I, well when I said I was normal at home. I'm generally normal kind of, I wouldn't be sensitive to things, but when I go out in public, depending on how uncomfortable I am, I notice sounds-behind me especially-I will be put on edge by them, by movement, peripheral vision movement. I will be noticing smells and sometimes when I am in a chair I will be kind of distracting myself with the texture of it".

► There is a direct correlation for him between how anxious he feels and how sensitive he becomes to sensory inputs. It is not, in his opinion, that he has improved sensory abilities in these instances, but rather his "attention to them" (Interviewee A) has increased

Sensory Issues in Public Spaces

- "I find if there's conversation's I find that I am paying attention to all the conversations at the same time and so I don't hear the people who are with me and I compensate for that by pretending to be deaf and asking them to repeat things". (Interviewee E)

- The sensory experiences of this interviewee are complex. He cites the examples of brushing against others on a busy street or people standing too close to him, as being very uncomfortable sensation's for him. However: "it's not an intimacy thing if I am sitting on a bus or a train that's very busy and the contact is firm against somebody, I don't mind that if they are not moving, sometimes I get pushed up against people and I don't like that".

Virtual Spaces as Public Spaces?

▶ Virtual space or cyber space exists both between and in public and private spaces. It is a public space that may be used for social interaction while being accessed from a private space

▶ Much research has shown the benefits of the internet for those with ASD (Armstrong, 2010).

▶ It has also facilitated the creation of the neurodiversity movement which began as, and continues to be, an online based movement.

▶ In this research paper one out of the seven participants uses the internet as a space to interact with others: "I use facebook to chat to certain people, one or two people that I am friendly enough with outside but I am a lot more friendly with on facebook, if they are usually on I would usually just start chatting straight away with them" (Interviewee D).

Virtual V Public Spaces

▶ The interviewee (D) uses a social networking site as a space to interact with certain people. He feels a preference for meeting face to face but this creates anxieties for him:

▶ "I probably prefer to meet people face to face but on the other side there's a bit of worry in me I guess sometimes it's just a bit safer to chat to them on the internet because...I am always able to keep a conversation going and not make any awkward gaffes...I am able to sit there for a couple of minutes and I am able to think about what I am going to say".

▶ This is in line with the view of numerous people with ASD in wanting to meet and interact with people: "Most of us also crave companionship" (Simone, 2010: 95).

The Limitations of Virtual Spaces

- He feels a sense of safety in the virtual space as it is a more forgiving space. For example the internet allows him time to process conversation. In this way he does not feel under the pressure of real time as he has a couple of minutes to process what he has been told and respond accordingly.

- Interviewee A feels that the internet as a space does not adequately convey all aspects of an interaction: "I find it difficult to talk to people when they can't hear the tone of my voice, it's more difficult when it's pure text...there's a kind of dimension of communication that's cut off when it's not spoken, for me".

- This opinion of the interviewee is contrary to much research posited around ASD and mindblindness which is the inability to read others thoughts, feelings and emotions, Baron-Cohen, (1995), and it serves to show the diversity of the ASD population (Baranek, 2002)

The Home Space and the Family

- "Home is somewhere comfortable and safe and I can more or less be myself and more or less be comfortable and relax with friends and stuff like that". (Interviewee E)

- "I suppose everyone in their house has their ups and downs, they might have rows with parents or be depressed or have problems at school but home is generally where the family are and you feel safe" (Interviewee C).

Home, Family and Conflict

- It is not only a space in which family issues may occur but is also a space which is infiltrated by issues that have occurred in other spaces. The home then becomes a site of potential conflict for issues that have not occurred in the home. There is therefore a blurring between the simple division of public and private spaces (Dyck and O' Brien, 2003).

- Interviewee C: "Sometimes when I feel a bit stressed in the past I might take it out on my parents in the past I might have rows with my siblings". This reveals the potential conflict that can take place in the home.

Contested Spaces in the Home

- The rest of the family home is seen by interviewee A as spaces of contestation and conflict. These spaces are unsafe and contain behaviours and rules that are unfamiliar to him. His two rooms also serve as a personalised space for the manifestation of his real self

- His sense that home is safer than public spaces and his two rooms are safer than the rest of the home is, while understandable, also potentially limiting and may lead to a form of confinement which may make the home a symbol for aspects of life which have been lost rather than a site of safety (Imrie, 2001: 32).

Home and Temporal Divisions

- For Interviewee E temporal factors dictate his experience of the home which he shares with his wife and children. For example when his children are at school: "I really like when everyone is out except me and the cat". However the space is changed for him in the evening time with the return of his family: "That's my space during the day time and during the evening time it's not my space anymore".

Controlling the Home

▶ Interviewee B articulates this view: "I am most comfortable in situations where I am in control of the environment because nothing is going to happen that is going to be unpredictable to me".

▶ "A completely empty space or an environment empty of people wouldn't be uncomfortable at all because it wouldn't matter how you are in that space and there is no one there to perceive you or judge you, as in, its like shopping on the internet no one can judge you for what you are doing". (Interviewee B)

Control and the Family

► Interviewee G:

► "I do feel insecure about my space when I have let people in, will say my family members and that, I also feel immediately vulnerable and insecure in that space, its like I want to be the only one walking around in that space and I don't want to let anybody in even if its just somebody to check on the boiler or that I already feel vulnerable".

Conclusion

▶ Societal expectations greatly influence peoples ability to interact

▶ Social spaces contain inherent difficulties for many with ASD

▶ Virtual spaces are not neccessarily the answer

▶ The home can be a contested space

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