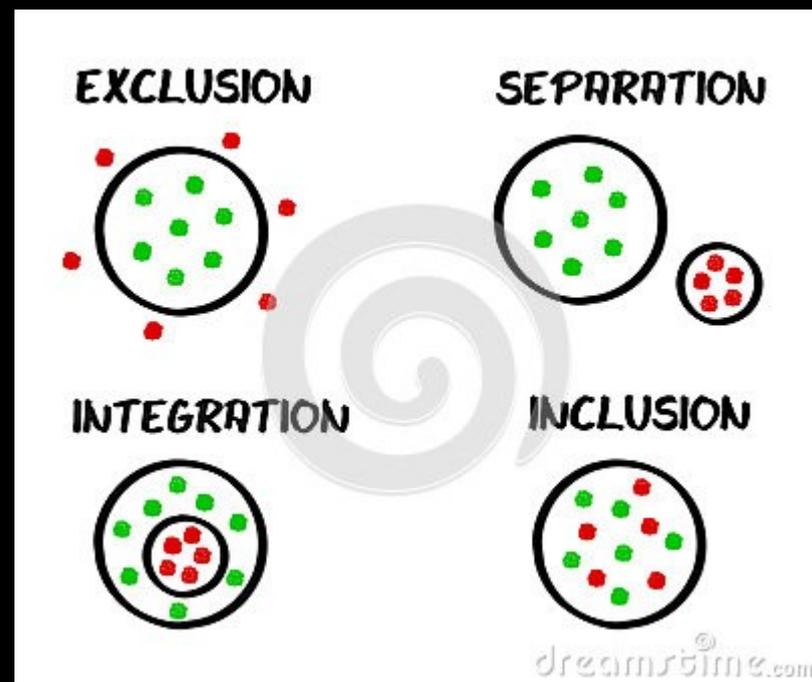


# What does an inclusive community space for autistic people involve?



), Dip(conv), PGCE, Mifl, MBPsS  
Doctoral Researcher – Autism Centre for Education and Research, University of Birmingham.  
Research Assistant – London South Bank University.  
Head of Autism Knowledge and Expertise (Adults and Community) – National Autistic Society.

- “Some of us aren’t meant to belong. Some of us have to turn the world upside down and shake the hell out of it until we make our own place in it.” (Lowell, 1999).



# A bit about me

- I'm autistic (diagnosed 2009) – as is my son (diagnosed 2005).
- A background in Social Science (initially Sociology).
- Studying for a PhD in the education of people on the autism spectrum.
- On the programme board of the AET.
- On the scientific committee for Research Autism.
- Researcher at London South Bank University.
- Head of Autism Knowledge and Expertise (Adults and Community) at the National Autistic Society.



# Introduction

- The terms 'inclusion' and 'community' conjure meanings that are contested and are interpreted in numerous and divergent ways.
- Contested meanings – particularly regarding 'inclusion'.
- Yet – which communities are we talking about and how are they formed?
- Inclusion, stigma, participation, belonging and community.

# Social stigma

- Those deemed outside the social norm – the discredited and the discreditable (Goffman, 1963).
- A 'spoiled identity'.
- Managing interactions with others – passing and rebelling.
- In-groups and out-groups (Tajfel and Turner, 1979).
- Social 'deviancy' and the formation of subcultures.

# Nothing about us, without us

- Having an autonomous voice – an essential requirement for individual well-being.
- For people on the autism spectrum however, there can be a number of barriers to participation in wider social life.
- People on the autism spectrum have often been excluded from contributing towards the decisions that directly affect their own lives.
- This has led many autistic-led advocacy groups to rally behind the slogan: 'Nothing about us, without us'.

# Aspects of social participation

- Acceptance and understanding – a sense of belonging.
- Engagement in public and political life – being able to express oneself and affect change.
- Individual and collective concerns.
- Present lived realities – a more collaborative future?

# Arnstein (1969)

Degrees of citizen power	Citizen control
	Delegated power
	Partnership
Degrees of tokenism	Placation
	Consultation
	Informing
No power / non-participation	Therapy
	Manipulation

# What do people mean by inclusion?

- “Being included in a group or structure.”
- Placement? Often neither inclusive or even ‘integration’.
- What does it mean to be part of a group when one is autistic?
- What helps an autistic person feel ‘included’ in something?

# Reasonable adjustment

- An alteration made to enable a disabled person to carry out normative responsibilities, such as the duties of a job role.
- Employers must make 'reasonable' adjustments to make sure disabled workers are not 'seriously disadvantaged' in performing their roles.
- 'Within reason' and normativity.
- In practice, alterations to cultural norms are often exceptions rather than the rule.

# Universal Design (UD)

- Originated in the field of architecture.
- Environments need to be designed to be accessed, understood and usable to the greatest extent possible by people of all ages, sizes and abilities.
- Not making 'special requirements' to meet the perceived needs of a specified grouping of people.

# Barriers to social involvement

- Barriers to autistic participation in society are often attributed to the autistic person's cognition or behaviour, rather than looking at the social barriers that can hinder such participation.
- Social participation is often constrained by systemic ableist practices.
- The framing of the autistic voice and the 'self-narrating zoo exhibit'.

# The 'double empathy problem'

- Building bridges between people of autistic and non-autistic dispositions is not always an easy process.
- The different perceptual worlds of the differently socially (dis)positioned (Milton, 2012, 2014, Chown, 2014).
- Empathy problems as a 'two-way street' (Sinclair, 1993).
- In this theory, it is not only the autistic person who struggles to read the intentions and motivations of non-autistic people, but the same can also be said in reverse.
- Theory of autistic mind can often leave a great deal to be desired.
- 'Fork 'andles'!



# Participatory research projects

- The Autism Education Trust (AET).
- The Ask autism project.
- The Theorising Autism Project.
- The Autonomy journal.
- The Cygnet mentoring project and the use of Personal construct theory (PCT).
- The Participatory Autism Research Centre (PARC) at London South Bank University.

# Wellbeing and belonging

Main themes	Sub-themes
Meeting personal needs	Autistic experience / Structure / Stress and sensory / Interests (and in Education) / Studying / Spirituality (philosophy) / Sexuality / Co-conditions
Living with the consequences of an othered identity	Bullying / Isolation and alienation / Exclusion / Mental Health (and psycho-emotional disablement) / Iatrogenesis (and blocking family) / Normalisation / Authority / Employment / Financial insecurity / Obedience and conformity / Ableism / Stigma / Identity / Diversity / Diagnosis / Women / Gender / Self-understanding / Disjuncture – ‘me and the I’ / Personal journey
Social navigation	Social navigation / Social expectations / Understanding (and lack of) / Double empathy problem / Appearances / Independence and autonomy / Masking and Passing
Connection and recognition	Connection and recognition / Voice and insider accounts / Community / Sharing interests / Autistic space / Authenticity / Acceptance
Relationships and advocacy	Family / Relationships / Mentoring / Researchers / Goal-oriented help / Needing advocacy

# My definition of inclusion

- Inclusion is not physical placement, but a feeling of belonging within a community of practice.
- Easier said than done, but not impossible...



# Communities of practice

## Types of Participation in Communities of Practice



adapted from Wenger, 2002

# Autistic-friendly and autistic-led space

- Beyond accessibility to mainstream social spaces.
- Autistic-led social groups and organisations.
- Autscape, ARGH, ASAN.
- Positive and negative experiences within the autistic community.

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