Autism Practice Today

WHERE ARE THE GAPS?

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The Autism Microsegmentation Study

• Funded by the Scottish Government through Scottish Autism

• Research group:

<table>
<thead>
<tr>
<th>At the University of Strathclyde</th>
<th>At London School of Economics</th>
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<tr>
<td>Prof Tommy MacKay</td>
<td>Prof Martin Knapp</td>
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<td>Prof Jim Boyle</td>
<td>Valentina Iemmi</td>
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<td>Michael Connolly</td>
<td>Amritpal Rehill</td>
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The Scottish Autism Survey

- The challenge: To get 200+ individuals with autism, their parents and carers to complete a highly detailed 30+ page questionnaire
- The response: 1,603 people responded, with complete data for about 1,000
- We now have possibly the richest data set in the world, covering diagnosis, comorbidities, educational placement, service provision, intellectual status, residential arrangements, employment... across the lifespan
- 1½ million cells of data – 8,000+ pages of tables
The Microsegmentation Study


A multi-strand investigation of microsegmentation of the autism spectrum.

*Good Autism Practice, 14, Supplement 1, 101-106*
Five gaps in autism practice today

• Diagnostic practice and provision
• Mental health and therapy
• Leisure and recreation
• Independence and public transport
• Criminal justice
Some of the things we don’t know

1 We don’t know how many people are on the autism spectrum

Two 2011 studies:
Al-Farsi (2011) 1.4/10,000 (0.014%)  Kim et al (2011) 264/10,000 (2.64%)

Dillenburger et al. (2015) 350/10,000 (3.5%)

• Almost every data point across that range is represented by one or more studies.
• Range for Asperger’s alone is 0.3/10,000 to 48.4/10,000 (with none in Baird et al., 2006)
• Conclusion: by chance expectation some of the worst studies will yield the truest prevalence rates.
2 We don’t know how many people with autism have an intellectual disability

• Estimates range up to about 83% (Oliveira et al., 2007)
• The most common estimate in recent years has been about 55% (see Baird et al., 2006)
Two new meta-analyses (MacKay, Boyle & Connolly, forthcoming)

1 Prevalence: we propose 1.04% (95%CI 0.99%-1.08%) as being the most reliable estimate of prevalence and a basis for budget planning and service provision

2 Intellectual disability: we propose that 32.7% (95%CI 27.0%-38.9%) of people on the autism spectrum have an intellectual disability
1 Diagnostic practice and provision

• Early diagnosis is crucial for planning educational provision, for intervention and for supporting parents and carers
• Median age of last 100 individuals diagnosed at the National Diagnosis and Assessment Service for ASD (child and adult) – to September 2016: 31 years
• Expected Scottish adult ASD population (age 18+) = 43,500
• Total recorded Scottish adult ASD population (the Scottish Autism Audit, 2004): 645
Under-diagnosis of children

- 3,400 children and young people diagnosed with autism in Scotland
- Prevalence rate: 35/10,000
- Expected prevalence: approx. 104/10,000

Gaps: Autism and diagnostic practice

• Waiting lists of 2 years + are not acceptable
• Effective strategies to move diagnosis from regional to local level are not being used (See McClure, MacKay, Mamdani & McCaughey, 2010)
• Adult diagnosis is vastly under-resourced
• Many teams have gaps in skills and training
• People fall into a gap between learning disability and mental health services
• Young people fall into a gap between child and adult services
2 Mental health and therapy

Is mental health a special issue for the autism spectrum?

<table>
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<tr>
<th>Type of mental health issue</th>
<th>ASD</th>
<th>General population</th>
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<tr>
<td>Emotional disorders</td>
<td>16%</td>
<td>4%</td>
</tr>
<tr>
<td>Emotional problems</td>
<td>51%</td>
<td>4%</td>
</tr>
<tr>
<td>Deliberate self-harm</td>
<td>25%</td>
<td>2%</td>
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Green et al. (2005) *Mental Health of Children and Young People in Great Britain.* London: ONS
Mental health: the scale of the problem

- Very high levels of anxiety for children and young people throughout the autism spectrum (Reaven et al., 2009, review of 40 studies)
- Diagnosed anxiety disorder at 55% for children age 6-12, with highest rates in Asperger’s Syndrome (De Bruin et al., 2006)
- High levels of depression across the spectrum (Stewart et al., 2006, systematic review)
- Up to 65% of adolescents with Asperger’s Syndrome have clinically significant levels of anxiety, depression and anger (Gillot, Furniss & Walter, 2001; Green, Gilchrist, Burton & Cox, 2000)
- High prevalence of all mental health disorders for adults (Howlin & Moss, 2012; Lugnegard et al., 2011; Mattila et al., 2010)
When therapy does harm

• Lack of trained staff with expertise in therapy for ASD
• Lack of ASD-specific therapeutic resources

The case of DL

DL is a 15 year old boy who with autism who suffered PTSD following a minor accident in a bus in which he was travelling. He became unable to travel on buses and then on any vehicle.

He was offered therapy by a CBT therapist using a standard protocol. This traumatised him further and he became frightened to leave the house. There is virtually no one with therapeutic expertise for ASD.
Therapy: the challenge

‘There is limited access and poor uptake of psychological treatment services by people with autism due to:

- limited availability and
- interventions not adapted for use for people with autism’

(NICE, 2012, para. 4.2)
The Homunculi

A Flexible CBT Programme for Young People on the Autism Spectrum or with Emotional and Behavioural Difficulties

*The Homunculi* is an evidence-based, autism-specific programme designed to take account of theory of mind, weak central coherence, executive function and affective theories of autism
Mental Health of Teenage Boys with AS

- Pre
- Post

- Anxiety
- Depression
- Anger
- Stress
Research study (N=20) (MacKay & Greig, 2008)

Briere Trauma Scales (1996)
(Effect Sizes shown)

Anxiety (0.67)
Depression (0.98)
Anger (0.97)
Stress (0.95)
[A video clip showing feedback on the impact of the Homunculi programme from a group of six teenage boys with Asperger’s Syndrome was shown here]
Inclusive approaches in mainstream: Using The Homunculi with whole classes (Greig, MacKay & Nolan, forthcoming)

<table>
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<tr>
<th>Mean anxiety score</th>
<th>Homunculi (n=23)</th>
<th>Controls (n=22)</th>
<th>F</th>
<th>Significance</th>
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<tr>
<td>Pre</td>
<td>31</td>
<td>28</td>
<td>7.216</td>
<td>p = 0.01**</td>
</tr>
<tr>
<td>Post</td>
<td>23</td>
<td>27</td>
<td></td>
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• The Homunculi class showed significantly lower anxiety scores following the intervention
3 Leisure and recreation

The significance of leisure and recreation

• Leisure and recreation central to quality of life
• Leisure and recreation central to general development
• The Dead Poets’ Society
Maslow's Hierarchy of Needs

- Physiological
- Safety
- Love
- Esteem
- Self-actualisation
Needs for leisure and recreation in ASD

• Limited access to normal range of social opportunities
• Less likely to make or sustain friendships
• Less motivation to have friendships
• Inability to mix with others in ordinary settings
• Inability to adapt to rules and expectations of these settings
• Inability to cope with noise, crowds
Leisure and recreation: A Scottish study
(MacKay, Marwick & Tait, 2004)

• Sample: every child and young person on the autism spectrum in a large Council area

• Interviews with parents, professionals and young people

Wishes of parents: removal of barriers; access to provision; better awareness of staff and public; better supervision; more information on services

Wishes of young people: to have normal social contact; to have friends; to be understood; to be independent; to be included
The value of leisure and recreation

• Limited access can lead to loneliness, social dissatisfaction, aimlessness, depression, anxiety and suicide (Brewster & Coleyshaw, 2011)
• Leisure activities with others can help social and language skills (Orsmond & Kuo, 2011)
• Leisure activities help in creation of adult identity (Brewster & Coleyshaw, 2011)
Gaps: Leisure and recreation

- Inaccessibility of mainstream services
- Lack of awareness of staff and public of ASD needs
- Lack of supervision
- Lack of information on services
- Lack of autism-specific services
- Insufficient research (NCBI database: 5,296 references for autism; 5 for autism + leisure and recreation)
4 Independence and public transport

Key issues for people on the autism spectrum

• Transport mobility is crucial for independence, social inclusion and employment
• Fewer people with autism have cars or a driving licence
• More people with autism are unable to use public transport
• Difficulties include: fear of getting lost, of attack and of being unable to cope; not being able to utilise information (maps, schedules); not having adequate visual and auditory cues
Transport and autism: great needs, few studies

- ‘A greenfield site’ (MacKay, 1991: *Psychology and the development of passenger transport policy*)
- CEOs of Passenger Transport Executives (UK):
  - proposed professional input ‘relevant’ or ‘very relevant’
  - actual professional input: ‘little’ or ‘none’
- Little change in last 25 years: a paucity of studies published
- Main advances have been for physical and sensory disability (low floor entry, wheelchair space, tannoy systems)
Gaps: Autism and public transport


- an urgent need to fill gaps in the research

- an urgent need for supports for people with ASD
5 Autism and criminal justice

Key issues

Please note: the case examples shown at the talk cannot be included as some of the individuals might be identified

• ‘An appropriate adult’
• Understanding the caution
• Giving evidence in court
• False confession
• Diagnostic issues

• Behaviour in the community
• Mens rea
• Treatment programmes
• Life in prison
Understanding the caution

Issues for people on the autism spectrum

• verbal fluency exceeding comprehension
• working memory deficits
• speed of processing
• conforming to expectations of authority
• desire to please
• wish to appear well informed
• wish to escape the interview as quickly as possible
False confession

Issues for people on the autism spectrum

• suggestibility (‘May I put it to you that...’)
• belief in the truthfulness of others (‘Miss R has told the court that there was no doubt that your actions amounted to rape...’)
• undue compliance with authority
• the wish to escape from the immediate situation
• total confusion under stress
Behaviour in the community

Issues for people on the autism spectrum

• lack of insight
• failure to understand social rules
• pursuing strange and unusual interests
• impulsivity
Gaps: Autism and criminal justice

• There is an urgent need for research into criminal and forensic issues in autism

• Much work needs to be done so that the criminal justice system can meet the needs of individuals on the autism spectrum
The Autism Charter: How do the gaps measure up?

DIAGNOSIS
‘The right of people with autism to an accessible, unbiased and accurate clinical diagnosis and assessment’

MENTAL HEALTH
‘The right of people with autism to appropriate counselling and care for their physical, mental and spiritual health’

LEISURE
‘The right of people with autism to participate in and benefit from culture, entertainment, recreation and sport... and to have equal access to and use of all facilities, services and activities in the community’
TRANSPORT  ‘The right of people with autism to accessible transport and freedom of movement’

CRIMINAL JUSTICE  ‘The right of people with autism (and their representatives) to legal representation and assistance and to the full protection of all legal rights’

‘The right of people with autism to freedom from fear or threat of unwarranted incarceration’
Should we be gloomy about the gaps?

• ‘The only time you should ever look back is to see how far you’ve come’ (Anonymous)

• ‘Is it much longer to go?’ he asked wearily.
  ‘Yes’, came the reply. ‘But it’s shorter longer than when we started.’
  (Tanglewood Tales)