NORTHERN IRELAND LIFE AND TIMES SURVEY: AUTISM MODULE

PROF. KAROLA DILLENBURGER, DR JULIE-ANN JORDAN, DR LYN MCKERR, CILLIAN MCKERR
(FUNDED BY OFMDFM)
OUTLINE

• Autism Spectrum Disorder
• BASE Project
• Results from the ASD module in NILTS
• A mother’s perspective
• A personal perspective
**Diagnosis:**
- No medical diagnosis
- Direct observation and parent/caregiver reports
- Behavioural ‘excesses’ and/or ‘deficits’ in
- social communication, restricted interests and repetitive behaviours

**Co-occurrence:**
- Intellectual disability (25 - 70%)
- Mental health issues, e.g., ADHD (30%)
- Physical, e.g., Gastrointestinal (GI) (3.5x more), epilepsy (20-30%)
Prevalence: 1:88 (CDC, 2012); 1:50 children (CDC, 2013)
Interventions:

Local: Eclectic approach
(Task Group Report, 2002)

International: Applied behaviour analysis-based interventions
(US Surgeon General, 1999; National Standards Project, 2009)
Prognosis

• Lifelong? Adults with autism
• Optimal Outcomes (OO) data
  – 47% indistinguishable from typical developing peers after early intensive behaviour analysis-based interventions (EIBI; Lovaas et al., 1987)
  – 18% of children diagnosed aged 2, receiving (mostly behavioural) intervention lost diagnosis by age 4 (Sutera et al., 2007)
  – OO participants no longer met criteria, predominantly received behavioural interventions (Fein et al., 2013)
  – Up to 25% appear to lose the diagnosis (USA); the % who would have reached this outcome without intervention remains unknown (Helt et al., 2008)
The Autism Act NI (2011):

Amend Disability legislation to include ‘communication’ and ‘social relationships’


Consultation closed 15 March 2013
Publication expected later this year
OUR RESEARCH SO FAR

- Dillenburger and McKerr (2009). *What the Future Holds: Older people caring for adult sons and daughters with disabilities*
- Dillenburger and McKerr (2011). *Sons and daughters with disabilities: Childcare issues across the lifespan.*

(Completed project reports free download from www.qub.ac.uk/cba)
Families of sons/daughters with disabilities

– Concerns about life-skills, mobility, communication and challenging behaviour
– Well informed about effectiveness of evidence-based practice
– Ambitious for sons/daughters’ prospects/potential
– Carefully selective regarding services; respite/short breaks and daycare are important services
LIFESPAN ISSUES

Early years:
• Diagnosis
• Severe lack of services
• including lack of early intensive behaviour analysis-based interventions (EIBI).

Middle years:
• Organiser/manager
• Worry about the future,

Latter years:
• Decreasing levels of care giving support from extended family
• Extreme worry about future, yet almost 70% have not made firm future plans
BASE PROJECT
(BENCHMARKING AUTISM SERVICE EFFICACY)
PROF. KAROLA DILLENBURGER, DR JULIE-ANN JORDAN & DR LYN MCKERR
(FUNDED BY OFMDFM)
AIMS OF BASE PROJECT

To inform the Autism Act (NI) 2011 and associated ASD strategy and action plan

• By providing baseline data on a range of issues prior to the full implementation of the cross-departmental ASD strategy and action plan;

• By developing benchmarks designed to monitor progress and facilitate decision-making
Phase 1: The literature review

Relevant published research focusing on poverty, education and employment;
Policies and strategy reports from Government Departments, educational institutions and employers.
Phase 2: The NILTS Autism Module:

Northern Ireland Life and Times Survey (NILTS) in collaboration with ARK:

To collect quantitative baseline data on awareness, knowledge, attitudes, and behaviours among the general public (n=1200)
Phase 3: Secondary Data Analysis

To utilize existing relevant and available data sets,

Especially with regard to disability and poverty, employment, education, quality of life, and economic impact of policy.
Phase 4: Primary Qualitative Data Collection

Active engagement, focus groups, interviews, and questionnaires with stakeholders.

Including individuals with ASD, caregivers, employers, educators, health and social care staff, policy makers.
NILTS RESULTS: AUTISM MODULE

DR JULIE-ANN JORDAN
AUTISM MODULE

• NILTS Design
  – N=1,204
  – Adults from NI Households
  – Figures weighted by household size

• Autism module
  – Awareness of autism
  – Knowledge of strengths/challenges associated with autism
  – Personal contact with people affected by autism
  – Attitudes towards adults with autism in social, employment and educational contexts
  – Beliefs about parenting and autism
  – Optimal outcomes
  – Views on effectiveness of services and interventions
AUTISM AWARENESS

- Yes: 82%
- No: 16%
- Don't know: 2%
STRENGTHS ASSOCIATED WITH AUTISM

- affectionate
- art
- creative
- determined
- focused
- gifted
- intelligent
- maths
- memory
- music
- special-talent
- unsure
- variation
- very-intelligent
- loving
*61% of the sample knew someone with autism
JOBS FOR INDIVIDUALS WITH AUTISM

Views on suitable employment

[Bar chart showing views on suitable employment for various roles, with the y-axis ranging from 0% to 100%. The bar chart includes roles such as Doctor, Lawyer, MP/MLA, Waiter/waitress, Computer programmer, Labourer, Artist/Musician, Stock shelves, and Sheltered employment. The bars are color-coded, with light blue indicating "Yes, if high functioning" and dark purple indicating "Yes".]
CUSTOMER BEHAVIOUR

More likely to shop there: 12%
Would make no difference: 86%
Less likely to shop there: 0%
Don't know: 0%
Other: 1%

e.g., Supermarket employs someone with Autism
Acceptance of people with autism

- Appointed as your boss: 70% comfortable if high functioning, 30% comfortable
- Marries your relative: 80% comfortable
- Appointed as your colleague: 90% comfortable if high functioning, 10% comfortable
- Moved in next door on own: 90% comfortable if high functioning, 10% comfortable
Views on parenting and autism

- Strongly agree: 0%
- Agree: 3%
- Neither agree nor disagree: 4%
- Disagree: 28%
- Strongly disagree: 56%
- Don't know: 8%
Views on whether autism is a life-long disability

Strongly agree: 4%
Agree: 18%
Neither agree nor disagree: 12%
Disagree: 44%
Strongly disagree: 14%
Don't know: 8%
INTERVENTIONS

Views on effectiveness of interventions

Drug treatments: 50%
Behavioural intervention: 77%
Other non-drug related therapies: 74%
Nothing can help: 4%
People with autism don't need help: 4%
ROLE OF SERVICES

<table>
<thead>
<tr>
<th>Views on departmental responsibility</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>An educational issue</td>
<td>26%</td>
</tr>
<tr>
<td>A health issue</td>
<td>33%</td>
</tr>
<tr>
<td>Both</td>
<td>28%</td>
</tr>
<tr>
<td>Neither</td>
<td>3%</td>
</tr>
<tr>
<td>Don't know</td>
<td>11%</td>
</tr>
</tbody>
</table>
KEY POINTS

• High levels of public awareness of autism
  • 80+% are aware of autism, of these 60+% have family member or friend/acquaintance with autism
• Good level of ‘knowledge’ about strengths and challenges
• Openness to include individuals with autism in community, employment, education
• Potential for increases in use of businesses who employ individuals with autism
• Positive attitudes towards parents who have children with autism
• Support for behavioural interventions, but still some confusion about evidence-based practice
• Confusion about who is responsible for service delivery, health, education or both.
A PARENT’S PERSPECTIVE

DR LYN MCKERR
ATTITUDES 1990s

• Is he very spoilt?

• Oh yes, they just parrot what they hear, it sounds very clever until you realise they don’t understand any of it

• Sure, if they could learn, they wouldn’t be at a special school
RECENT COMMENTS FROM PARENTS

• People are much more understanding, [statutory agencies] have become more disability friendly. People are generally much more aware

• Yeah, perhaps there is a growing awareness or trend...

• I can see in the last 17 years it has improved… they are aware of it more but I wouldn’t say they accept it any better.
I feel embarrassed, but I feel embarrassed for her as well. People don’t understand, you know, they’re looking at you funny, you feel really, really bad…

You were constantly explaining or apologising or trying to set a strategy in place for all the things that could happen before they even happened.
IMPACT

• We can’t do those things, normal family days out… it’s not always a success and they’ll end up screaming the place down

• If he takes a tantrum it is going to impact on other people that would be close by. So we just didn’t go anywhere…
AWARENESS RAISING

- (RASDN) 2009 – all Trusts autism awareness training for families and key staff

- Autism Act (NI) 2011
- Cross-departmental Autism Strategy 2013

- QUB: Masters in ASD
- Centre for Behaviour Analysis; QUART Annual Conferences and frequent high calibre workshops

- Research
WHAT HELPED?

Increased positive media coverage due to
• Active voluntary groups
• Novels, plays, blogs, articles in papers
• World Autism Awareness Day & International Autism Speaks’ *Light It Up Blue* campaign
LOCAL- AND GLOBAL!
KEY POINTS

• Results of NILT survey a confidence booster for parents and people with ASD

• Families - go out when you want to, enjoy the things everybody else is doing

• Adults - get involved in community and work

• Vast majority of public won't be judging or condemning you
A PERSONAL PERSPECTIVE

CILLIAN MCKERR
STUDENT LIFE

• A levels- revising hard for History, English Literature, ICT

• 3year course for BSc in Politics with Criminology- waiting for results..
WHERE DO WE GO FROM HERE?

• Unemployment in the UK has risen significantly since 2008
• It is harder to find a job now than in the previous 5 years
• Recent austerity policies- I may not get as much support as I would have previously.
PROBLEMS WITH JOBS

• I tend to need directions on what to do
• I don’t have a social worker - not all employment schemes apply
• I have a tendency to panic, when not sure about what to do.
• Getting on the job ladder is more difficult with employers asking for “experience”
EXPERIENCE – SO FAR

• 1 week data inputting (Work Experience)
• 3 weeks as intern, volunteering at Fresher’s Fair, 3 days for a financial company (EDGE)
• Driving lessons
• Support from Autism Initiatives applying for part-time jobs
• Signed up for Pathways-Choices
WHAT CAN I OFFER?

- Good educational grounding
- Computer literate
- Hardworking (in the right environment)
- When given a suitable task, can finish it
- Capable of working in a team
- Seems the public welcome people with ASD in the workplace - now it’s time for employers
ACKNOWLEDGEMENTS

• To parents/caregivers, individuals with autism and with LDs and to service providers from both voluntary and statutory services who responded to the previous research projects
• To OFMdFM and to ARK