



NORTHERN IRELAND LIFE AND TIMES SURVEY: AUTISM MODULE

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(FUNDED BY OFMDFM)

OUTLINE

- Autism Spectrum Disorder
- BASE Project
- Results from the ASD module in NILTS
- A mother's perspective
- A personal perspective

AUTISM SPECTRUM DISORDER

Diagnosis:

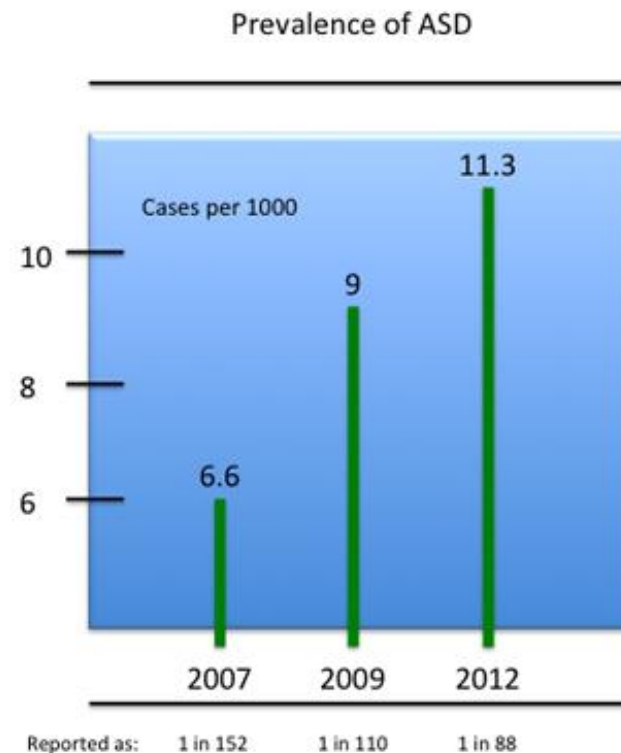
- No medical diagnosis
- Direct observation and parent/caregiver reports
- Behavioural 'excesses' and/or 'deficits' in
- social communication, restricted interests and repetitive behaviours

Co-occurrence:

- Intellectual disability (25 - 70%)
- Mental health issues, e.g., ADHD (30%)
- Physical, e.g., Gastrointestinal (GI) (3.5x more), epilepsy (20-30%)

AUTISM SPECTRUM DISORDER

Prevalence: 1:88 (CDC, 2012); 1:50 children (CDC, 2013)



AUTISM SPECTRUM DISORDER

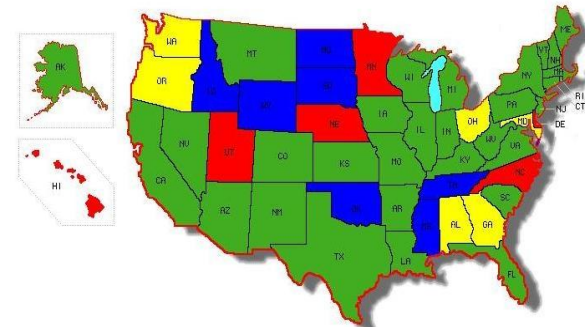
Interventions:

Local: Eclectic approach

(Task Group Report, 2002)



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



AUTISM SPECTRUM DISORDER

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)

ASD IN NORTHERN IRELAND

The Autism Act NI (2011):

Amend Disability legislation to include
'communication' and 'social relationships'

Cross-departmental Autism Strategy (2013 - 2020) and Action Plan (2013 - 2015)

Consultation closed 15 March 2013

Publication expected later this year

OUR RESEARCH SO FAR

- Keenan, Dillenburger, et al (2007) *Meeting the Needs of Families Living with Children Diagnosed with Autism Spectrum Disorder*
- 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)

FINDINGS

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)

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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

4 PHASES OF BASE PROJECT

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.

4 PHASES OF BASE PROJECT

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)

4 PHASES OF BASE PROJECT

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.

4 PHASES OF BASE PROJECT

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.



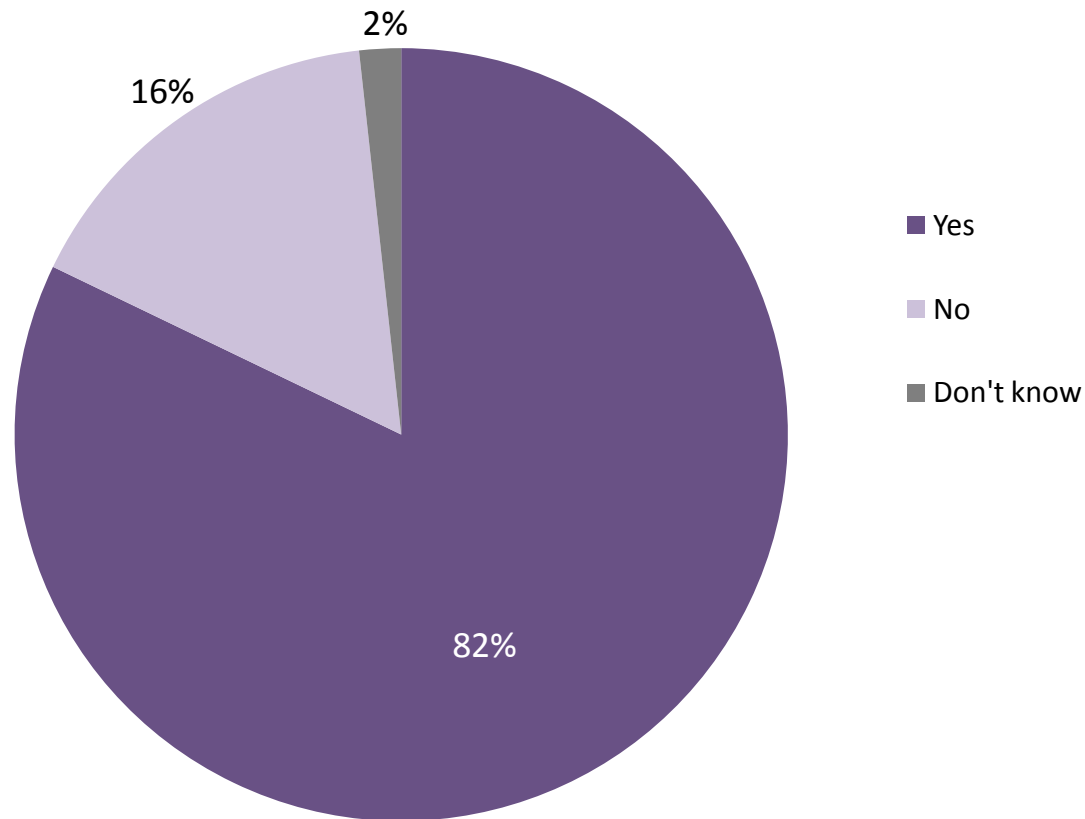
NILTS RESULTS: AUTISM MODULE

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

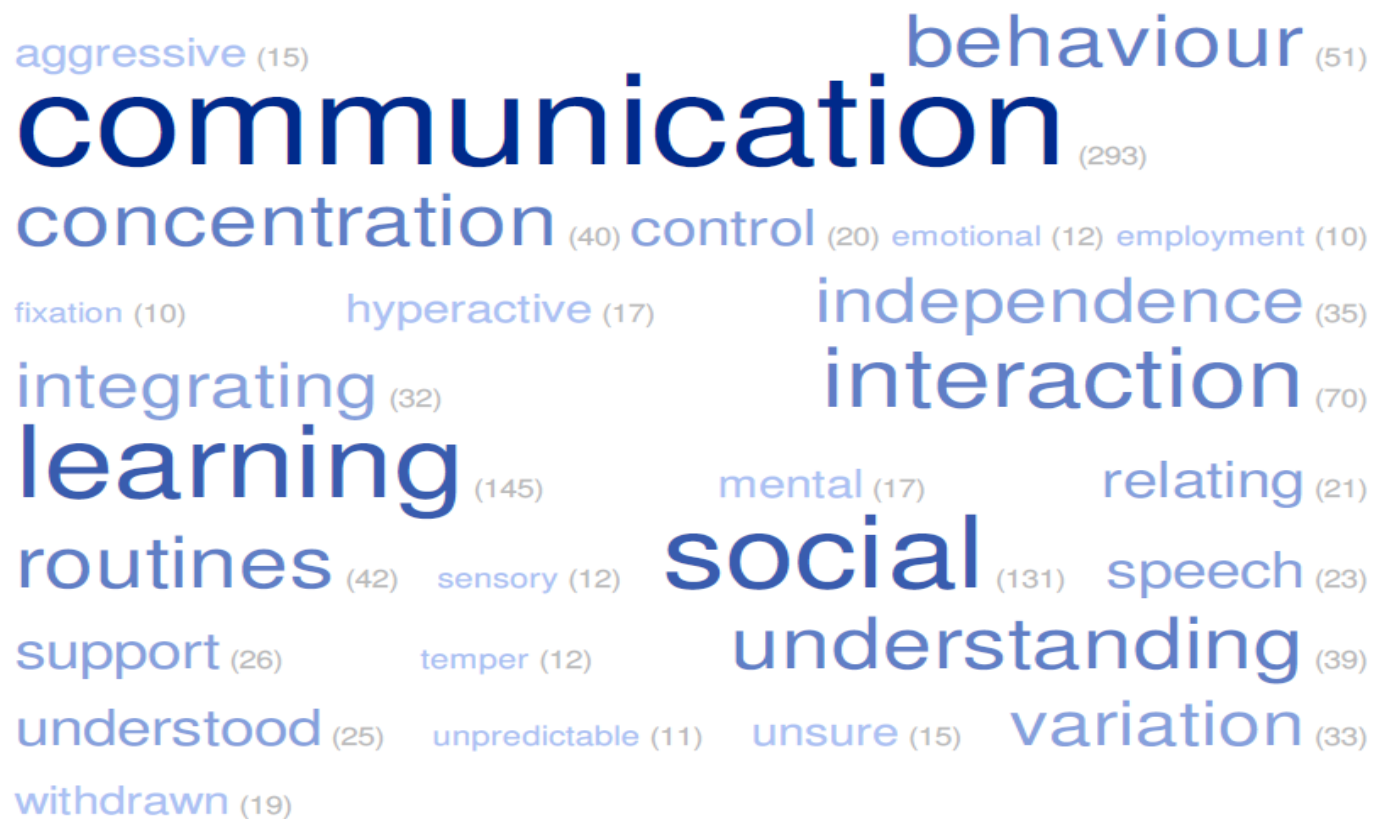
AUTISM AWARENESS



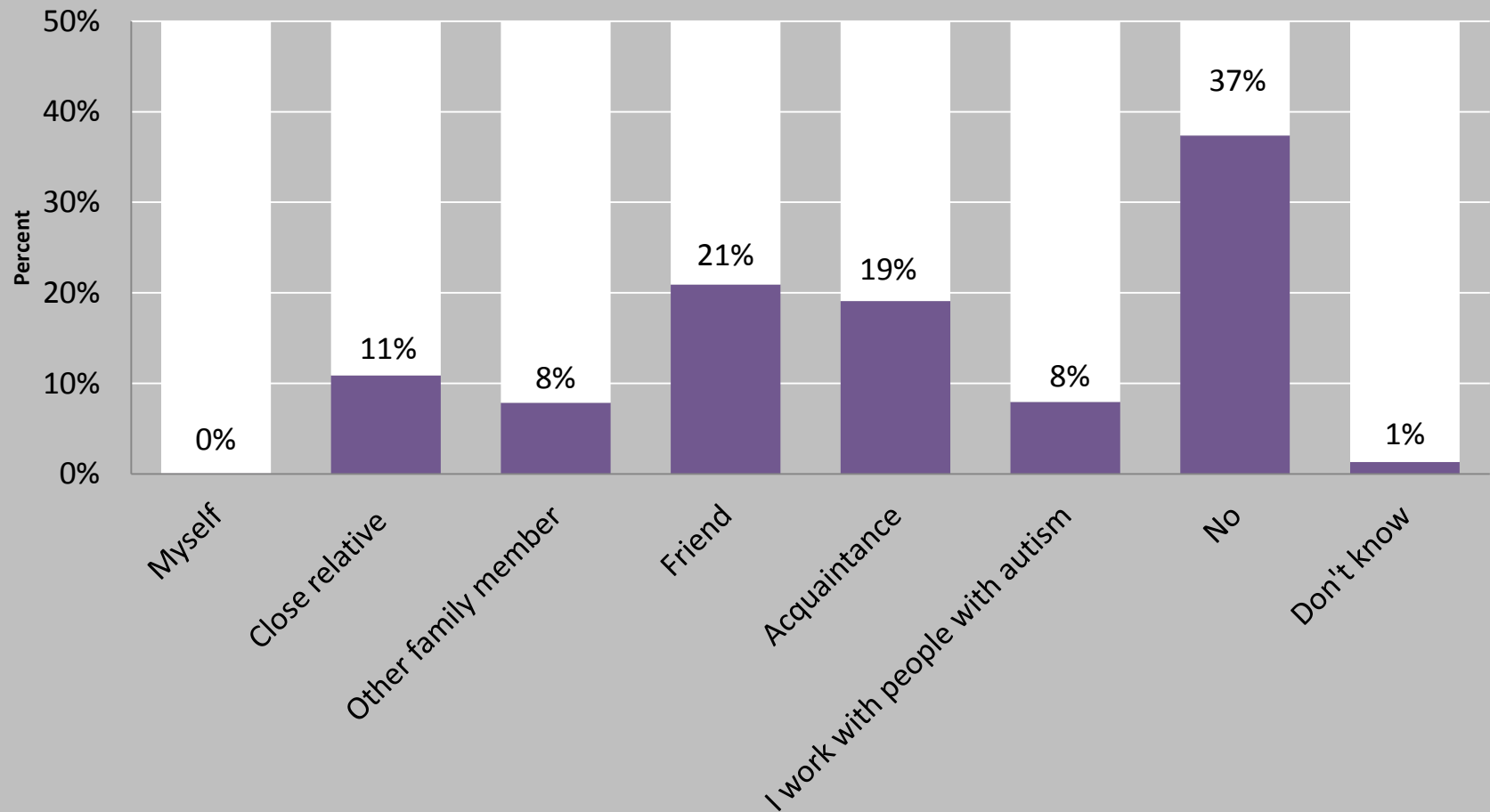
STRENGTHS ASSOCIATED WITH AUTISM



CHALLENGES ASSOCIATED WITH AUTISM

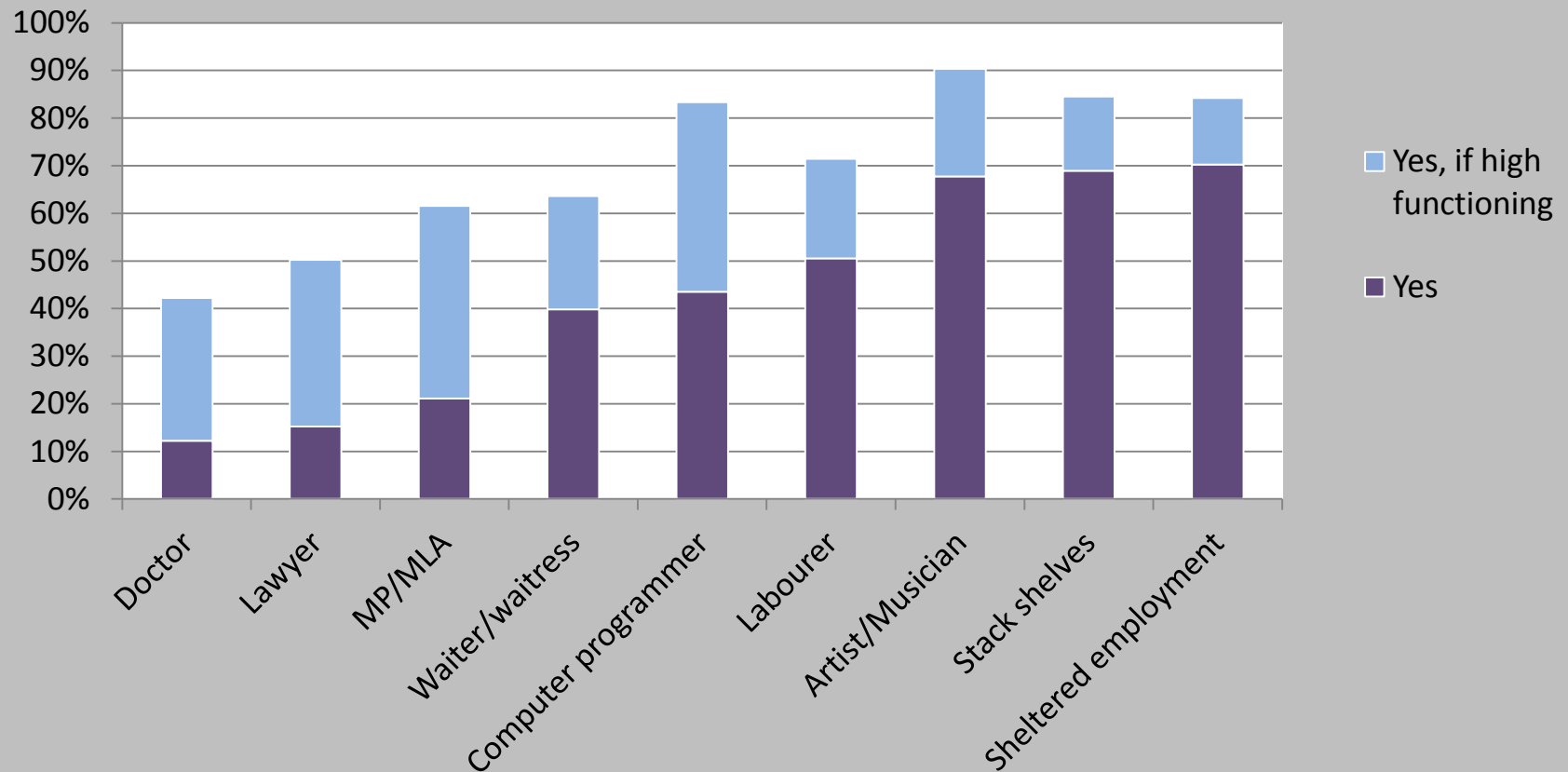


PERSONAL CONTACT



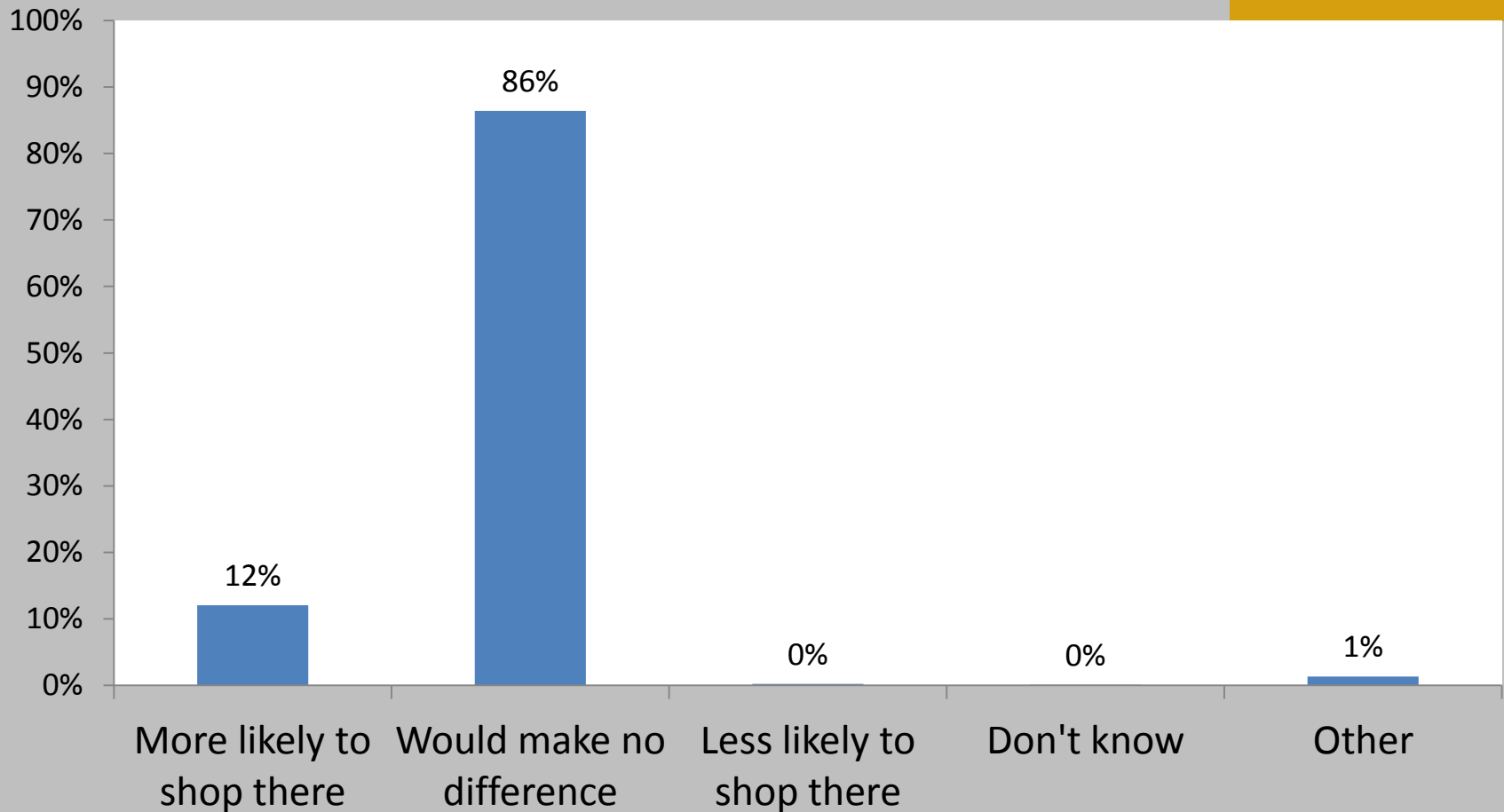
*61% of the sample knew someone with autism

JOBS FOR INDIVIDUALS WITH AUTISM



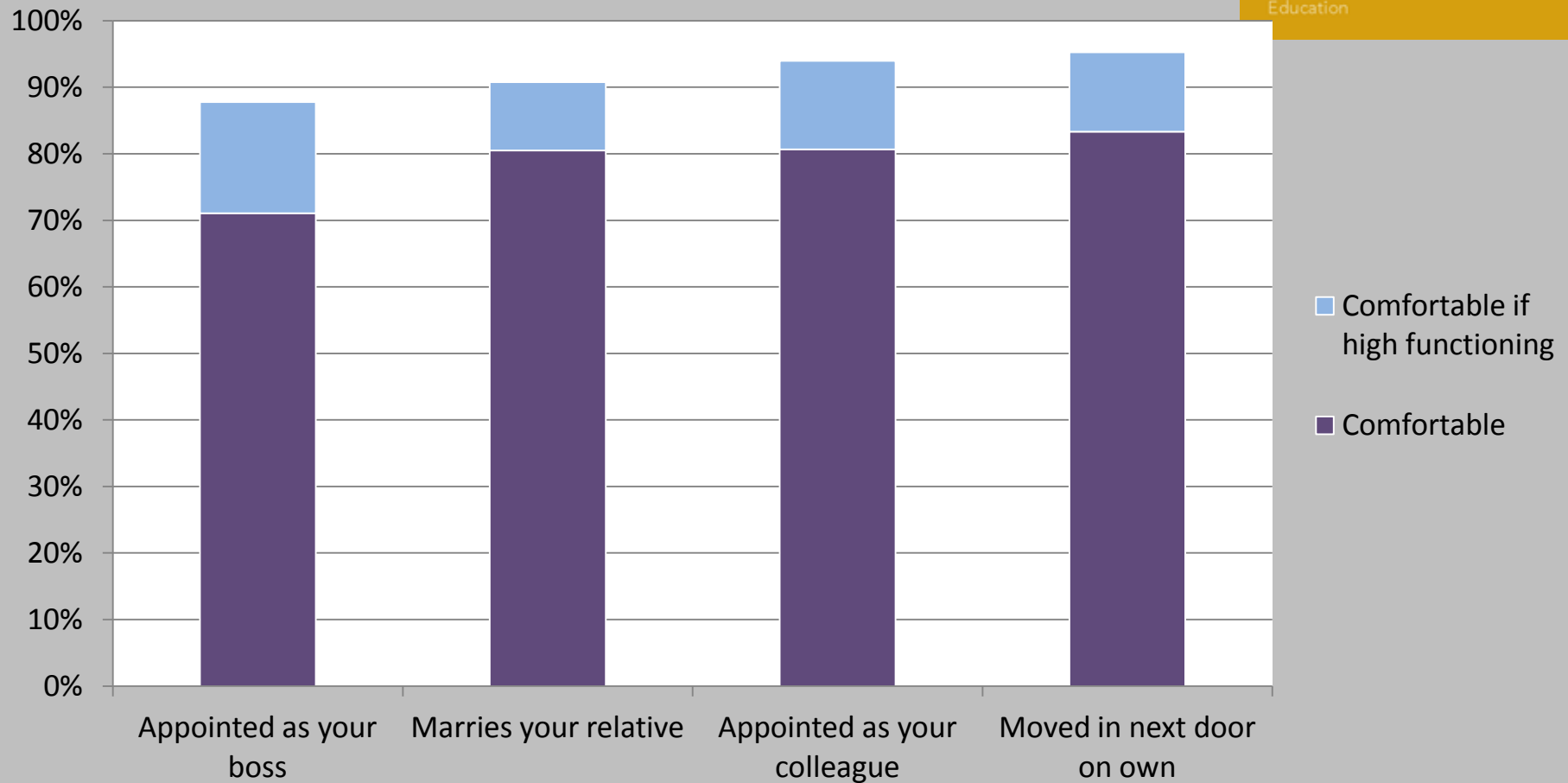
Views on suitable employment

CUSTOMER BEHAVIOUR



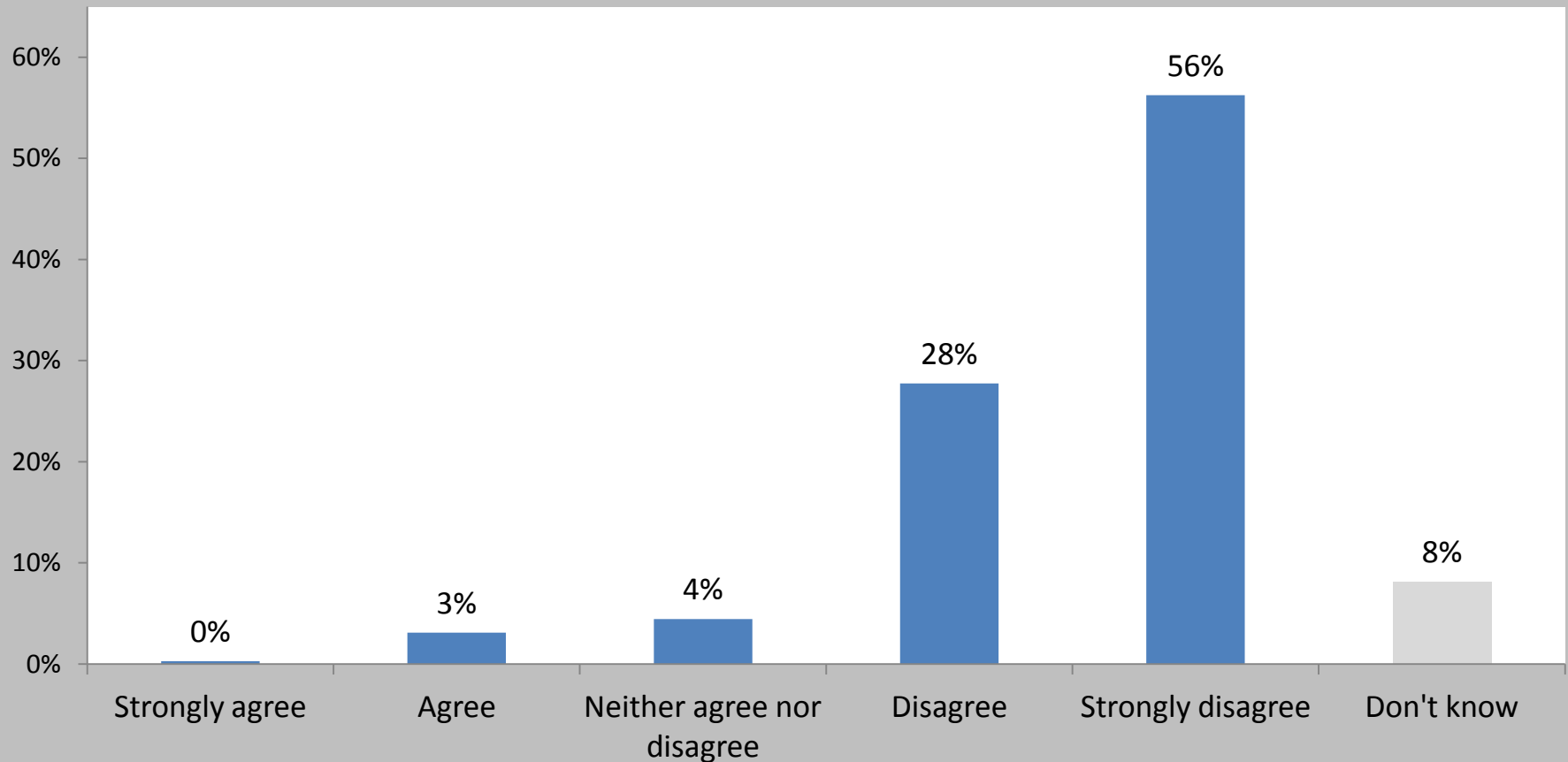
e.g., Supermarket employs someone with Autism

SOCIAL SITUATIONS AND EMPLOYMENT



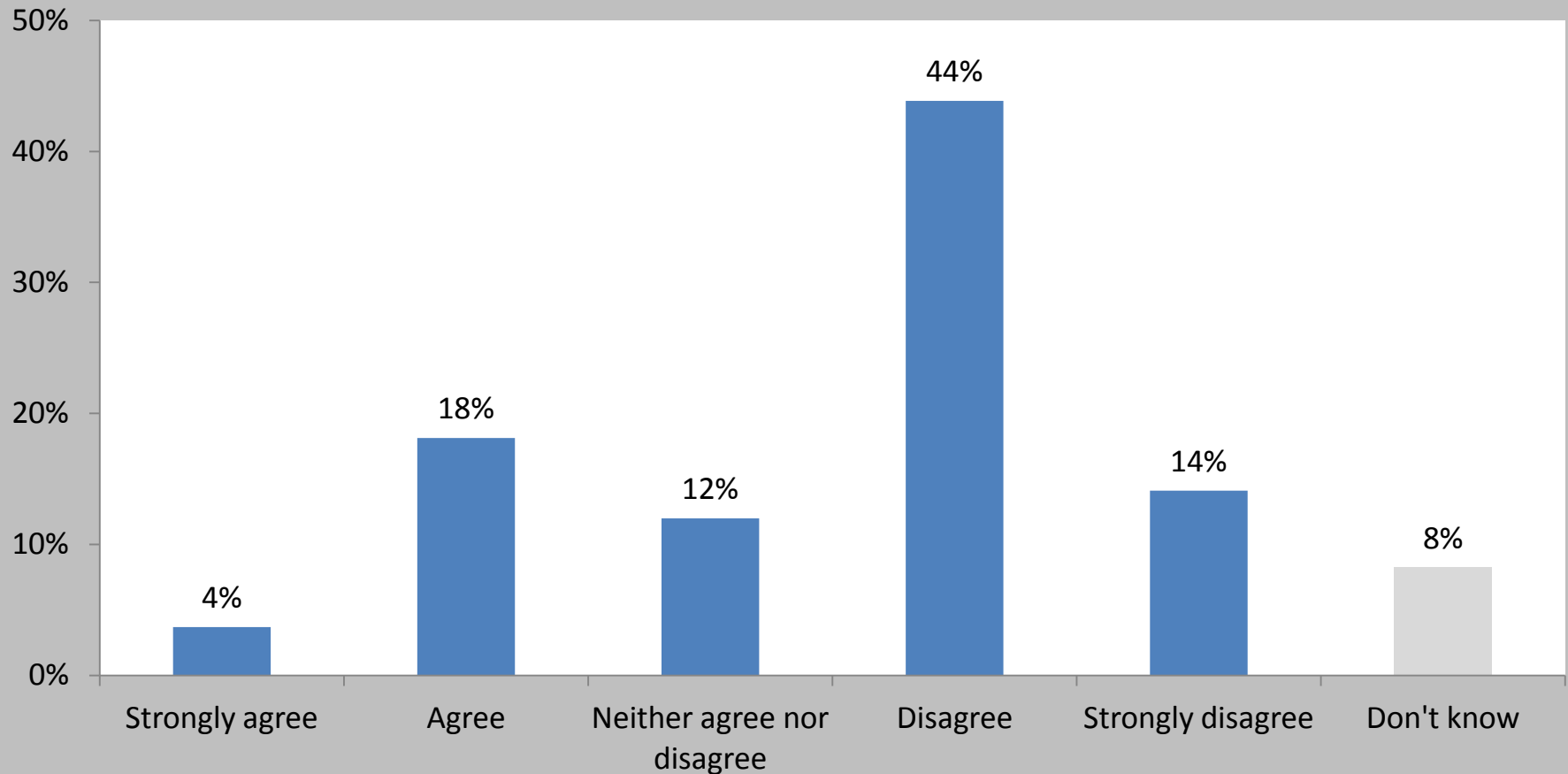
Acceptance of people with autism

PARENTS



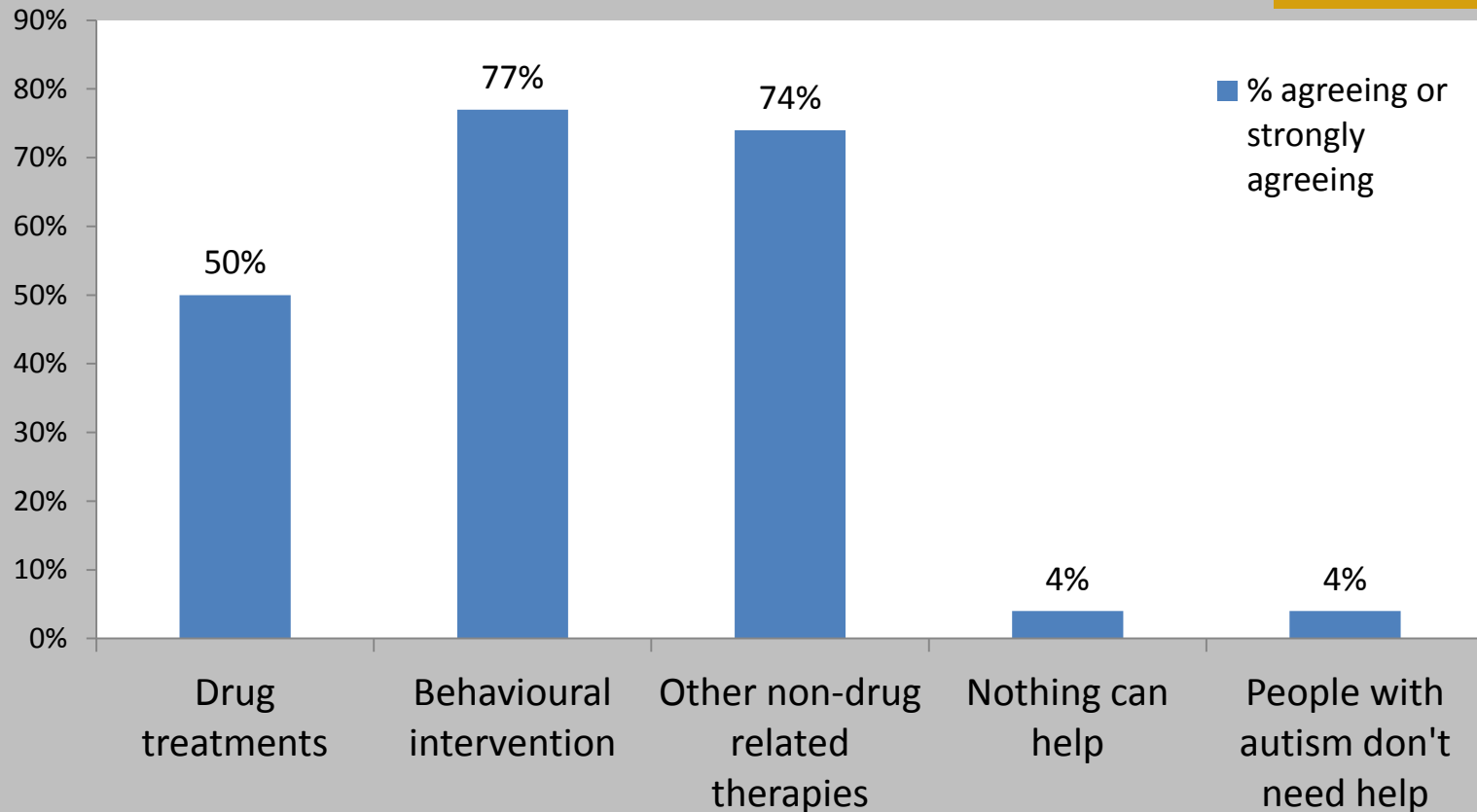
Views on parenting and autism

OPTIMAL OUTCOMES



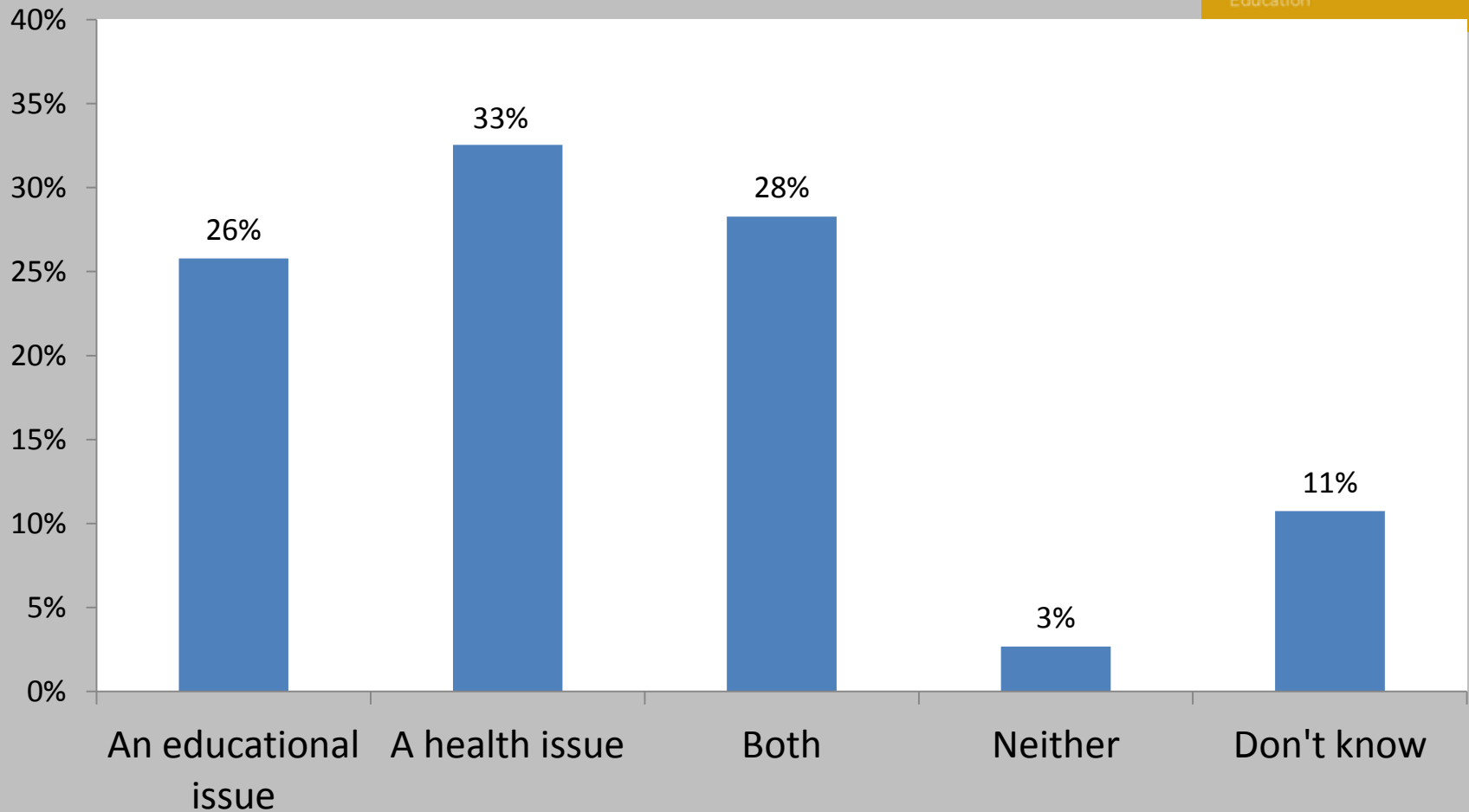
Views on whether autism is a life-long disability

INTERVENTIONS



Views on effectiveness of interventions

ROLE OF SERVICES



Views on departmental responsibility

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.*

OTHER PEOPLE'S EXPECTATIONS?

- 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.*



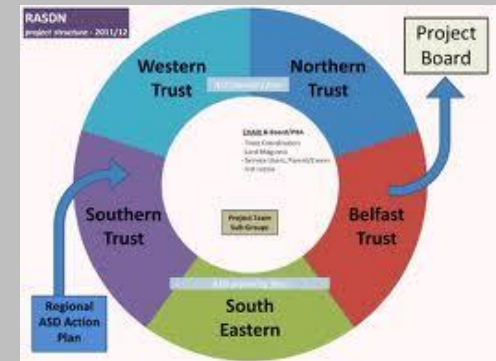
IMPACT

- *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