Scoping review on autism

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Overview of the presentation

- Scoping review approach

- Definitions and prevalence

- Strategic context

- Evidence base for service models and interventions

- Training

- Research possibilities from the literature

- Next steps

Scoping reviews

- This type of review provides a preliminary assessment of the potential size and scope of available research literature

- It aims to identify the nature and extent of research evidence

- Identify areas where a full systematic may be needed

- Don't tend to include process of quality assessment

- Cannot usually be regarded as a final output in their own right

(Grant and Booth, 2009)

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Scoping review methodology

- Searched Google Scholar, National Institute for Health and Care Excellence (NICE) Evidence Search, Zetoc, Social Care Online and Web of Science

- Main search terms: "autism"; "autism spectrum disorder"; "Asperger's"; "high functioning"; "systematic review"; "Northern Ireland"

- Selection: focused on systematic reviews if available, most recent research and innovative service developments

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Definitions and prevalence

- "Autism is a lifelong disability which affects the way an individual relates to people, situations and their immediate environment. The term Autism Spectrum Disorder (ASD) is often used because the impact of autism varies from person to person." (NI Executive, 2013, p. 16)

- "Autism is lifelong and affects the social and communication centre of the brain. Autism affects the way an individual relates to people, situations and the immediate environment. Many individuals with autism have difficulty processing everyday sensory information like sight, smells, touch, tastes and sounds. Autism is a spectrum condition, it will affect people in different ways depending on the individual and varies from person to person." (Autism NI, https://www.autismni.org/about-1)

Definitions and prevalence

- "A complex neurodevelopmental condition, autism is characterised by difficulties in the social use of verbal and non-verbal communication which result in functional limitations in social participation and educational/occupational performance. The difficulties must have been there since early childhood even in cases where diagnosis is made at a later stage (DSM 5).

- Due to the potential range of associated symptoms, autism is typically called Autism Spectrum Disorder (ASD). There is huge diversity in the population who have been diagnosed as ASD. The presence and extent of additional learning difficulties will have a significant impact on the challenges faced by the person with Autism." (HSE, 2018, p. 4)

Definitions and prevalence

- "Diagnostic manuals, ICD-10 and DSM-5, set out the criteria for autism to be diagnosed. These create the foundation for diagnostic tools such as the DISCO (Diagnostic Interview for Social and Communication Disorders), the ADI-R (Autism Diagnostic Interview - Revised), the ADOS (Autism Diagnostic Observation Schedule) and 3Di (Developmental, Dimensional and Diagnostic Interview).

- The ICD-10...presents a number of possible autism profiles, such as childhood autism, atypical autism and Asperger syndrome. These profiles are included under the Pervasive Developmental Disorders heading, defined as "A group of disorders characterized by qualitative abnormalities in reciprocal social interactions and in patterns of communication, and by a restricted, stereotyped, repetitive repertoire of interests and activities. These qualitative abnormalities are a pervasive feature of the individual's functioning in all situations." (National Autistic Society, www.autism.org.uk/advice-and-guidance/topics/diagnosis/diagnostic-criteria/all-audiences)
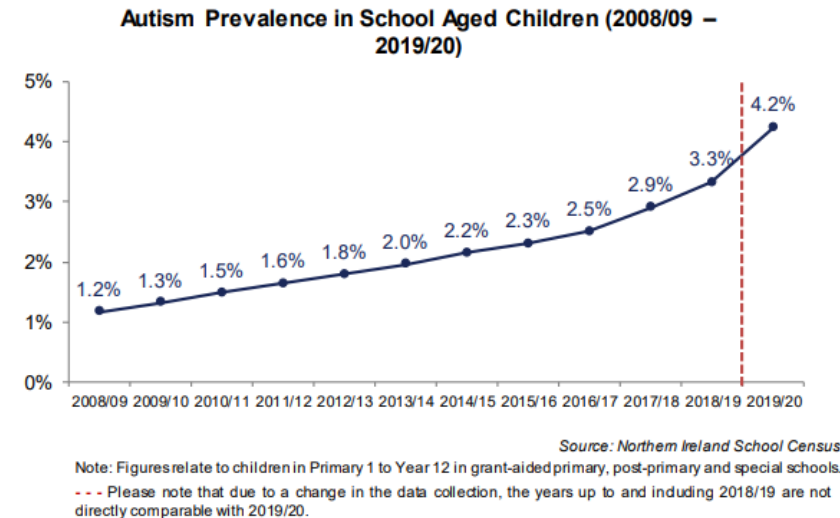
Definitions and prevalence

- "In Northern Ireland, 1 in 24 children have a diagnosis of autism (2020, Prevalence of Autism in School aged children, DHSSPS). Accurate prevalence figures for adults can be a difficulty as there are many adults who do not have a formal diagnosis of autism and therefore statistics can be misleading.

- Approximately 25% of individuals with autism will have an accompanying learning disability.

- Statistics show that there are approximately four males diagnosed with autism for every one female diagnosed. However, we know that it is sometimes harder to diagnose females with autism and therefore this statistic can hide the true number of autistic females."

- (Autism NI, https://www.autismni.org/statistics-1)

Definitions and prevalence

- In the Autism Strategy "estimated prevalence rate of 1.8% for children and 1.1% for adults equating to approximately 5,000 children and 15,000 adults currently being affected by autism in NI." (p. 18)

- Prevalence of Autism in School aged children (DoH, 2020) prevalence rate of 4.2% for school aged children

Autism Prevalence in School Aged Children (2008/09 – 2019/20)

Source: Northern Ireland School Census
Note: Figures relate to children in Primary 1 to Year 12 in grant-aided primary, post-primary and special schools.
- - - Please note that due to a change in the data collection, the years up to and including 2018/19 are not directly comparable with 2019/20.

- The mental health of children & parents in Northern Ireland - Results of the Youth Wellbeing Prevalence Study, October 2020

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Young People at Risk of other Mental Health Problems - Autism

AQ-10 Question (Child Version)	Subscale
often notices small sounds when others do not	Attention to detail
usually concentrates more on the whole picture, rather than the small details	Attention to detail
In a social group, he or she can easily keep track of several different people's conversations	Attention switching
finds it easy to go back and forth between different activities	Attention switching
doesn't know how to keep a conversation going with his or her peers	Communication
is good at social chit-chat	Communication
When he or she is read a story, he or she finds it difficult to work out the character's intentions or feelings	Imagination
When he or she was in preschool, he or she used to enjoy playing games involving pretending with other children	Imagination
finds it easy to work out what someone is thinking or feeling just by looking at their face	Social skills
finds it hard to make new friends	Social skills

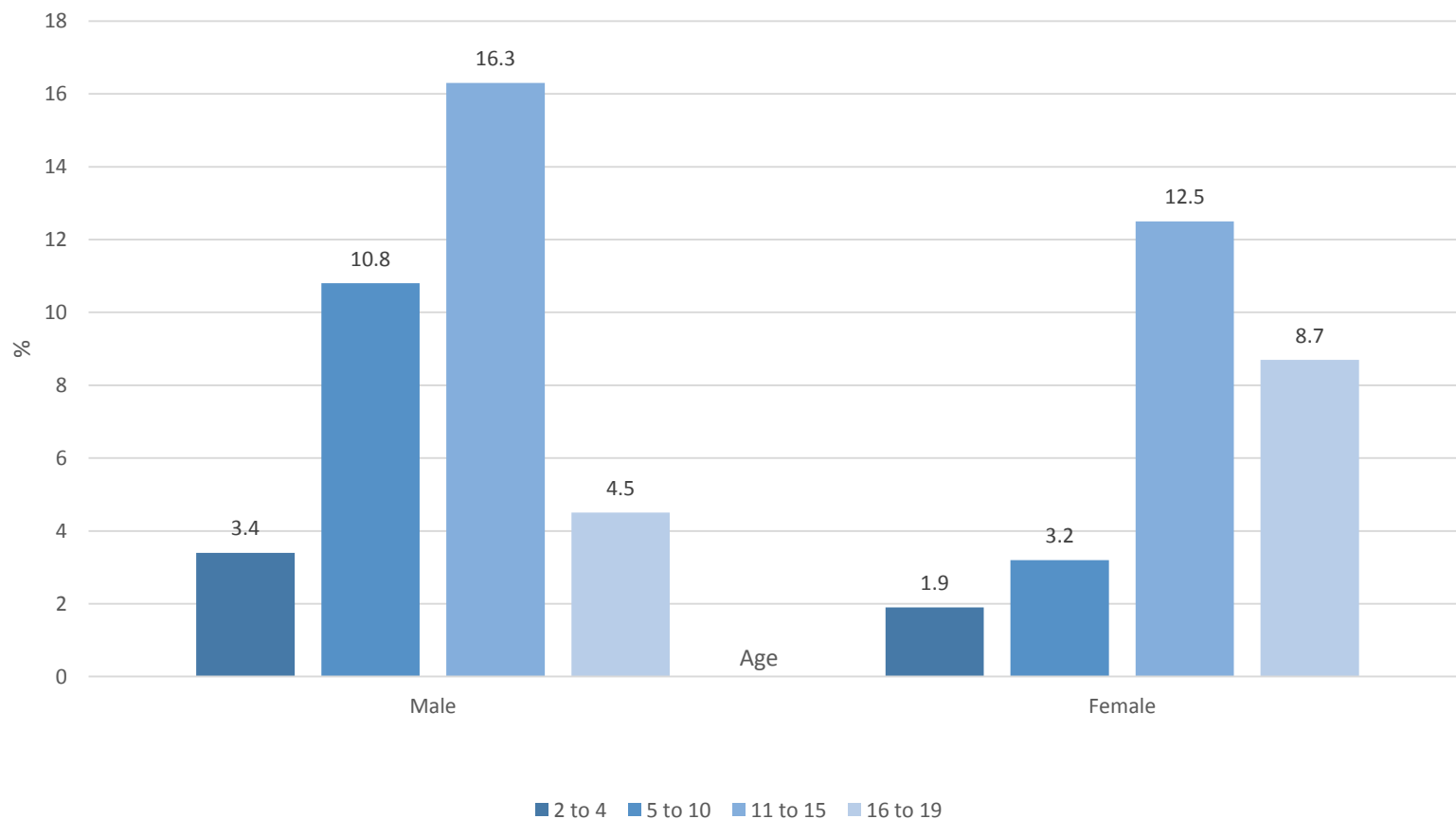- Measures:
    - Parents of 2-3 years olds (Modified Checklist for Autism in Toddlers, Revised (M-CHAT-R; Robins et al., 2014)
    - Parent of 4-15 years olds used parent report version of the Autism Quotient (AQ-10; Allison et al., 2012)
    - Young people aged 16-19 years use and the adult self report version of AQ-10.
- Global estimates of 7.1 per 10,000 for typical autism and 20.0 per 10,000 for all ASD related disorders (Williams, Higgins, & Brayne, 2006).
- The MHCYP survey (Sadler et al., 2018) in England identified 1.3% of 5-15 year olds as meeting the criteria for Pervasive Developmental Disorder (PDD) or Autism Spectrum Disorder
- NI had the highest prevalence in the UK, 3.2% of all students in 2018-19, and as with other nations, rates have increased over time, doubling from 2009/10 (McConkey, 2020).
- Typically boys have significantly higher rates than girls

M-CHAT/AQ RESULTS

7.74% of children and young people were identified as being at risk of autism

Prevalence estimates were significantly higher for males than females (9.2% vs 6.1%)

Rates were highest for the 11-15 year old age group (16.3% of males; 12.5% of females)

There was no statistically significant relationship with deprivation and risk of autism, although rates trended downward as deprivation decreased

Autism Spectrum Disorders by Age & Gender

Male: 2 to 4 = 3.4, 5 to 10 = 10.8, 11 to 15 = 16.3, 16 to 19 = 4.5

Female: 2 to 4 = 1.9, 5 to 10 = 3.2, 11 to 15 = 12.5, 16 to 19 = 8.7

Legend: ■ 2 to 4 ■ 5 to 10 ■ 11 to 15 ■ 16 to 19

Definitions and prevalence

- Autism, ID, physical health and mental health

- Autism and common mental health conditions – systematic review found prevalence rates of 4%-28% (Lai et al., 2019)

- Systematic review found 4.5–25.1% of children with ID were reported to have autism (Oeseburg et al. 2011), with higher rates with severe ID

- Another systematic review of adults with ID reported prevalence of autism of 8–30% (Emerson and Baines 2010), also higher with more severe ID

- Co-occurring intellectual disabilities and autism had odds ratio = 48.8 (45.0–53.0) in statistically predicting poor health (Dunn et al., 2019)

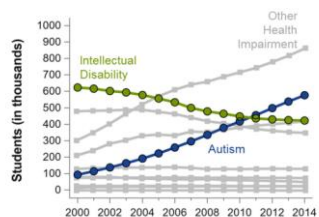- Some concerns re overlap between ID and autism (Thurm et al., 2019)

Strategic context

- NI – Autism Act (NI) 2011 – DoH has a statutory obligation to prepare, review and monitor the implementation of a cross-departmental strategy setting out how the needs of autistic people and their families are to be addressed throughout their lives.

- NIE (2014) Autism Strategy 2013-2020 and Action Plan 2013-2016 – Awareness; Accessibility; Children, young people and family; Health and wellbeing; Education; Transitions; Employability; Independence, choice and control; Access to justice; Being part of the community; Participation and active citizenship

- DHSSPS (2015) Autism Strategy Progress Report

- National Autistic Society and Autism NI (2016) Broken Promises

- DoH (2018) Autism Strategy Progress Report

- "It is intended that the new regional framework developed by the HSCB will underpin the next phase of cross-departmental working and, importantly, stakeholder engagement around the future of autism services." (p. 14)

Strategic context

- HSE, 2012, Autism Review

- HSE, 2012, New Directions Review

- HSE, 2018, New Directions National Framework

- HSE, 2018, Review of Health Services for Individuals with ASD

Strategic context

- England – House Of Commons Library Briefing Paper Jan 2020

- Autism Act 2009; Think Autism Strategy 2010 and 2014; consultation and review 2019 and 2020; NHS Long Term Plan 2019: NICE guidance

- "The Government and NHS have also focused on reducing levels of inpatient care for people with a learning disability and/or autism. The Department of Health and Social Care has said that hospitals are not where people should live and committed to move people to community based support. However, ambitions for this have been postponed. The most recent target, as detailed in the NHS Long Term Plan, is for a reduction in inpatient provision of 50% (compared to 2015 levels) by 2023/24.

- The Government has also committed to introducing mandatory training on learning disabilities and autism for health and social care staff. Trials will begin in health and social care settings by April 2020, and report by March 2021, after which wider roll-out of training is expected for all staff." (pp. 3-4)

Evidence base for service models and interventions

- HSE, 2018, good summary of evidence base:

- "Intervention for Children with ASD

- NICE (2011) Intervention Guidelines - With regards to the structure of interventions, the NICE (2011) guidelines recommend that:

- service users be allocated personalised care plans (as formulated by their inter-disciplinary teams) based on their needs rather than their diagnosis. Such plans outline (1) postdiagnostic support required by the individual and their families; (2) preventative courses of action through psychosocial interventions to minimise triggers of maladaptive behaviours based upon behavioural principles and guided by a prior functional analysis of the individual's behaviour; (3) supports for integration into the community/ mainstreaming, e.g. educational or employment; and (4) needs for specialist services for any co-morbid disorders such as intellectual difficulties." (p. 6)

Evidence base for service models and interventions

- HSE (2018): New Zealand Autism Spectrum Disorder Guidelines (2016) - These guidelines make a number of recommendations including treatment which supports functional development in the form of independent living skills, treatment of co-morbid conditions, behavioural management techniques, interventions to address communication issues and community based support groups.

- Scottish Intercollegiate Guidelines Network (SIGN, 2016) - The SIGN (2016) guidelines make a number of recommendations for ASD interventions including parent mediated interventions, communication interventions, cognitive/emotional skills training, occupational therapy and nutritional interventions.

- Applied Behaviour Analysis – Centre for Behaviour Analysis

Evidence base for service models and interventions

- HSE (2018) – Intervention with Adults with ASD - NICE

- "For the assessment of challenging behaviour, it is recommended that a functional analysis is conducted for the purpose of identifying what is triggering and maintaining such behaviour. Such an assessment forms the basis for the development of tailored psychosocial interventions based on behavioural principles to target such behaviour.

- Group based social skills intervention delivery (NICE, 2011)

- NICE guidelines (2011), also recommend adults presenting without a learning disability, or with a mild intellectual disability should be provided with a personalised employment programme, facilitating mainstreaming.

Evidence base for service models and interventions

- HSE (2018) - Behavioural interventions target challenging behaviour and adaptive functioning (NICE, 2011, SIGN, 2016).

- "NICE (2011) guidelines recommend that CBT can be used in intervention for adults with ASD with the following adaptations: a more concrete approach using written and visual information such as worksheets or thought bubbles to make the process less abstract; placing increased emphasis on changing behaviour rather than thought processes; explicitly stating content and rules; using simple, clear, direct language and maintaining the persons engagement by scheduling regular breaks and incorporating individual interests into therapy." (p. 8)

- NICE (2014) quality standard - antipsychotic medication should not be first line treatment for behaviour.

Evidence base for service models and interventions

- What do Cochrane systematic reviews say about interventions for autism spectrum disorders? (Lyra et al., 2017)

- "Seventeen reviews were included. These found weak evidence of benefits from acupuncture, gluten and casein-free diets, early intensive behavioral interventions, music therapy, parent-mediated early interventions, social skill groups, Theory of Mind cognitive model, aripiprazole, risperidone, tricyclic antidepressants and selective serotonin reuptake inhibitors (SSRI); this last only for adults. No benefits were found for sound therapies, chelating agents, hyperbaric oxygen therapy, omega-3, secretin, vitamin B6/magnesium and SSRI for children." (p. 192)

Evidence base for service models and interventions

- NICE (2012, 2016) ASD in adults "If residential care is needed for adults with autism it should usually be provided in small, local community-based units (of no more than six people and with well-supported single person accommodation). The environment should be structured to support and maintain a collaborative approach between the person with autism and their family, partner or carer(s) for the development and maintenance of interpersonal and community living skills." (p. 35-36)

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Training

- SPELL framework (Tizard Centre, 2018) provides a context for other approaches and a way of organising help through the environment and interactions:

- Structure – helping us to predict events.

- Positive approaches and expectations– helping us to achieve our potential.

- Empathy – helping to share the others point of view and

- experience.

- Low arousal – promoting good stress and avoiding bad.

- Links – helping us to be consistent.

Training – from the summary by MaryRose Martin

- "TEACCH - Treatment and Education of Autistic and Related Communication Handicapped Children (TEACCH) is a programme of intervention which utilises high levels of 'structured teaching' (Mesibov & Shea, 2009) and visual strategies. TEACCH aims to promote independence and skill acquisition for people of all ages and abilities (Van Bourgondien & Coonrod, 2013) with ASD and/or other language challenges, alongside the reduction of challenging behaviours.

- Augmentive and Alternative Communication (AAC) systems include both unaided systems e.g. sign language and aided, which require a device (e.g. Speech Generating Devices (SGD's) or Voice Output Communication Aids (Voca)).

Training – from the summary by MaryRose Martin

- "Makaton is described as falling into the category of unaided AAC as it is a method of supporting functional communication skill. It uses manual signs alongside verbal language and is based upon an 'open ended lexicon' (Lal, 2010, p. 120).

- Picture Exchange Communication System (PECS) is an image aided communication system for people with speech and language challenges. The use of PECS is most popular with those with ASD or other developmental disorders (Ganz et al., 2012).

- Paediatric Autism Communication Therapy (PACT) is a dyadic social communication intervention based upon the promotion of social interaction skills and reduction of restricted, repetitive behaviours in children with ASD. This uses video-feedback of interactive sessions between a child with ASD and a familiar adult."

- CBT, ABA, PBS

Research possibilities from the literature (NICE, 2016)

- What is the clinical and cost effectiveness of facilitated self-help for the treatment of mild anxiety and depressive disorders in adults with autism?

- What structure and organisation of specialist autism teams are associated with improvements in care for people with autism?

- What is the clinical and cost effectiveness of augmentative communication devices for adults with autism?

- Praxis PhD study just starting on: "A virtual reality and 360 video-based intervention for individuals with ASD and Social Anxiety" Susan Keery

Possible next steps

- Mapping of prevalence in Praxis service users

- Explore the SPELL framework

- Links with relevant organisations and researchers

- Identification of research priorities

- Propose possible PhD and/or specific projects

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