

27 September 2023

Studies

<u>'It wasn't the strategies on their own': Exploring caregivers' experiences of accessing services in the development of interventions for autistic people with intellectual disability</u>. Autistic individuals with intellectual disability are at greater risk of experiencing anxiety than their non-autistic peers without intellectual disability. Anxiety in this group may present as behaviour that challenges, often leading families to reach out to healthcare or support services. However, many families experience difficulties accessing services and, due to the lack of research into evidence-based anxiety interventions for people with intellectual disability, may not receive individualised support once in a service. This study explored caregivers' experiences of accessing services for autistic individuals with intellectual disability, and their considerations when developing new interventions for this population.

Social self-efficacy and mental well-being in autistic adults: Exploring the role of social identity

The double empathy problem proposes a lack of shared understanding between autistic and non-autistic people leads to interaction difficulties between them. Social self-efficacy (confidence in one's social abilities) makes an important contribution to social interactions. Research has shown that autistic people show a social identity (one's sense of self based on membership of social groups) with other autistic people, and this impacts positively on wellbeing. In addition, research shows that autistic people have a number of social identities. This study aims to understand whether social self-efficacy relates to mental well-being in autistic adults, and whether social identity plays a role in this relationship.

Increased rates of chronic physical health conditions across all organ systems in autistic adolescents and adults

The poorer physical health of autistic adults compared to non-autistic adults has been highlighted by several epidemiological studies. However, research has so far been limited to specific geographical areas and has primarily focused on young autistic individuals (aged 35 years and younger). Recent studies indicate a higher rate of mortality in autistic people, as well as poorer quality of self-reported healthcare interactions. This study aims to determine, first, whether autistic people experience greater levels of non-communicable health conditions and second, whether these are explained by differences in demographics (i.e. sex, country of residence, ethnicity, education level), alcohol use, smoking, body mass index (BMI), or family history of medical conditions.

Health policy narratives contributing to health inequities experienced by people with intellectual/developmental disabilities: New evidence from COVID-19

This paper discusses three cultural narratives that threaten the health of people with intellectual/developmental disabilities (IDD) and which have become more evident during the COVID-19 pandemic. These meta-narratives are the medical model of health/disability; the population health approach to health inequalities; and policies premised on the assumption of the importance of national economic growth as an incentive for reducing health inequalities. Evidence exists that health research is more likely to become policy if it fits within a medical model and addresses national economic growth. These two criteria are particularly problematic for people who have IDD. The paper also proposes a research model to facilitate the inclusion of IDD related issues in future policy regarding health inequalities.









challenging behaviour Disabilities a σ research health information carers Asperger Syndrome mental capacity intellectual disabilities



Community and Mental Health Services

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Development of the Impact of Diagnosis Scale–Revised (IODS-R)

quality of life

No tools quantify the experience, psychological, and practical impact of receiving a diagnosis from a non-deficit perspective. Autism is increasingly late diagnosed in adulthood. The Impact of Diagnosis Scale (IODS) was initially developed for borderline personality disorder. We aimed to develop a revised version suitable for autistic adults and potentially other diagnostic groups. Following a trial of a preliminary revision, the researchers and autistic research advisors coproduced an expanded pool of 46 items, scored on 7-point Likert-type scale, within 6 hypothesized domains.

Gut microbiota signature in children with autism spectrum disorder who suffered from chronic gastrointestinal symptoms

Children diagnosed with autism spectrum disorder (ASD) frequently suffer from persistent gastrointestinal symptoms, such as constipation and diarrhea. Various studies have highlighted differences in gut microbiota composition between individuals with ASD and healthy controls of similar ages. However, it's essential to recognize that these disparities may be influenced by cultural practices, dietary habits, and environmental factors.

Reports

Mersey Care contributes to new King's Fund report

The King's Fund has published a new report into Independent Care (Education) and Treatment Reviews (IC(E)TRs). They are meetings intended to improve the treatment of people with a learning disability or autistic people in long-term segregation. As part of the research, The King's Fund interviewed clinicians, including staff from Mersey Care, who were involved in IC(E)TR meetings to find out what they thought of the meetings' planning, running on the day and the meeting recommendations.

Podcasts

Learning From Covid Learning Disability Event 11 September 2023

A workshop event has focused on sharing findings from a project on tackling inequalities in care for people with learning disabilities and autism. Reflecting on their Covid-19 pandemic experiences, a Social Care Institute for Excellence co-production group generated a set of critical lessons for social care commissioners. During the event, these lessons were shared and discussed - how can commissioners take them on board? In this mini podcast, hear from three of the delegates at the end of the event.

Blogs

Growing Older and Living with a Learning Disability

People with learning disabilities are more likely to develop dementia as they grow older according to the Social Care Institute for Excellence (SCIE) and they may also develop dementia at a younger age than non-learning disabled people. They may also experience deterioration from dementia at a faster rate than the general population.











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News

It's Time to Act on the Mental Health Bill

The Government published its draft Mental Health Bill last year, which proposed vital changes to the Mental Health Act. The bill is a chance to change outdated laws that define autism and learning disabilities as mental health conditions, and to introduce better protection for autistic people and people with learning disabilities.

Autism assessment waiting times

As of June 2023, 143,119 people were waiting for an autism assessment in England, new NHS data has revealed. This is a 47% increase in the number of people waiting in just one year.

Number of autistic people in mental health hospitals: latest data

The latest monthly Assuring Transformation NHS Digital data shows that in August 2023:

- In total 2,040 autistic people and people with learning disabilities are in inpatient mental health hospitals in England
- 1,325 (65%) of these people are autistic •
- There are 200 under 18s in inpatient units that are autistic or have a learning disability. Of these, 95% are autistic

New guidance on social prescribing for autistic people and people with learning disabilities A new report has revealed how social prescribing can benefit autistic people and people with learning disabilities and provides guidance for link workers and social prescribing services, people and their supporters, community groups, and commissioners and funders.

Just one quarter of TikTok videos about autism are accurate, research finds

Researchers are warning that information about autism which circulates on social media is not always accurate. The warning comes following a study published in the Journal of Autism and Developmental Disorders which found that just over one quarter (27%) of the most-watched TikTok videos on autism are accurate.

New report on SEND tribunals is published

A new report from the Disabled Children's Partnership and Pro Bono Economics, 'Wasting Money, Wasting Potential', sets out the money that is wasted by councils on forcing parents and carers of children with special educational needs and disabilities (SEND) to go to tribunal to get the right support.

Personalised assistive tech training course for professionals receives CPD certification

Learning disability charity Hft's face-to-face personalised technology training course, which aims to provide those who support vulnerable people with an awareness of assistive technology, has received CPD certification. Hft's course, titled 'Introduction to Personalised Technology (supporting people to lead their best lives possible)¹, is a three-hour training module covering topics such as what personalised technology is, implementing and managing technology, and ethical issues to consider.







