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Studies

<u>The Forgotten Voices: Enabling Children and Young People With Intellectual Disability to Express</u> <u>Their Views on Their Inpatient Hospital Experience</u>

The importance of enabling patients to provide feedback on their experience of healthcare is widely accepted but there are few appropriate measures to enable children and young people to directly provide feedback, particularly those with intellectual disability or younger children. Our primary aim was to develop and test patient-reported experience measures for children and young people with intellectual disability who use inpatient hospital services. A secondary aim was to test these measures with younger children aged 4–7 years without intellectual disability.

Access to healthcare for people with intellectual disability: a scoping review

People with intellectual disability experience stark health inequalities, often because of poor access to mainstream healthcare. This scoping review aimed to identify factors that influence access to healthcare for people with intellectual disability using Levesque and colleagues' comprehensive framework of healthcare access.

Rates, causes and predictors of all-cause and avoidable mortality in 514878 adults with and without intellectual disabilities in Scotland: a record linkage national cohort study. We aimed to quantify mortality rates, and causes, and identify factors (i.e., age, sex, Scottish Index of Multiple Deprivation (SIMD)) related to avoidable mortality in adults with intellectual disabilities.

<u>Citation Context Analysis of Autism Mortality and Suicide Findings From Hirvikoski's Landmark</u> <u>Study</u>

Understanding health outcomes, including mortality, is a high priority for the autistic community.1 High-profile publications and government reports state "people with autism die 16 years earlier"2 or have a "54-year life expectancy,"3 citing Hirvikoski and colleagues'4 landmark study of mortality among autistic people.

Evaluation of the patient profile and health interventions offered by a multidisciplinary Intellectual Disability health team

Specialised Intellectual Disability Health Teams enhance access to health services and improve intersectoral coordination. This study reviewed the profiles and healthcare recommendations for children and young adults with Intellectual Disability.

Adaptive Behavior, Self-Determination, and Health in Autistic Young Adults

Adaptive behaviour, self-determination, and health are important areas of body functions and activities identified by autistic adults as priorities for research. Past research has suggested that autistic adults have high support needs in adaptive behaviour and self-determination and have poor physical and mental health outcomes.

Common and unique menopause experiences among autistic and non-autistic people: A gualitative study

Autistic people face both similar challenges to non-autistic people as they navigate menopause and additional unique challenges. Semi-structured interviews with 15 autistic and 14 non-autistic adults (assigned female at birth), explored experiences of menopause.









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Navigating School Meal Environments: Perspectives of Pupils Diagnosed With Autism Spectrum Disorder or ADHD

Busy and unstructured school environments can present challenges for pupils diagnosed with autism spectrum disorder (ASD) and attention deficit hyperactivity disorder (ADHD). Although school restaurants may be demanding, limited research has focused on these pupils. This study explores how pupils diagnosed with ASD or ADHD navigate the physical, social, and pedagogical environments of school meals.

Out of Sight, Out of Mind—Explaining and Challenging the Re-Institutionalisation of People With Learning Disabilities and/or Autistic People

During the twentieth century, many countries underwent processes of 'de-institutionalisation' closing 'asylums' for people with mental health problems, learning disabilities and dementia. Despite this, the UK has witnessed a subsequent process of 're-institutionalisation' with the creation of new public/private sector facilities providing 'secure' care to large numbers of people, who can be residents for many years with no sense of when they may leave.

Avoidant/restrictive food intake disorder (ARFID) symptoms in gender diverse adults and their relation to autistic traits, ADHD traits, and sensory sensitivities

There is emerging evidence to suggest gender diverse people are overrepresented in avoidant/restrictive food intake disorder (ARFID) samples. However, the mechanisms underlying elevated risk for ARFID in this group are currently unknown. Gender diversity and neurodivergence commonly co-occur, with elevated sensory sensitivities reported to be a shared experience common across autism, attention deficit hyperactivity disorder (ADHD), and ARFID. We aimed to examine the unique contribution of sensory sensitivities, including hypoand hyper-sensitivity, in predicting ARFID symptoms in gender diverse adults, whilst controlling for autistic and ADHD traits.

Short report: Associations of family characteristics and clinicians' use of caregiver coaching in early intervention

There is a high demand for quality early intervention services for autistic children and their families. A key part of effective early intervention is teaching caregivers how to support their child's development through caregiver-mediated interventions. However, in publicly funded programs, these strategies are often not followed correctly. Some studies suggest that family characteristics may influence how well clinicians apply these coaching methods.

Teleassessment can overestimate the risk of learning disability in first and second grade of primary school

Early administration of reading, writing and math standardised tests allows us to assess the risk of developing a learning disorder and to plan a specific intervention. The ease of access to technological tools and past pandemic restrictions have led to the abandonment of face-to-face assessment in favour of teleassessment methods. Although these kinds of assessments sometimes seem comparable in the literature, their equivalence is not clearly defined.

'Like it's making my heart run': A strengths-based understanding of the play of autistic children

Autistic play is generally described from a deficit perspective where the players themselves have been overlooked. It is important to consult with autistic children themselves about their understanding of play. We asked autistic children about their views on play using many different creative ways that were chosen by the children themselves.









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Atypical audio-visual neural synchrony and speech processing in early autism

Children with Autism Spectrum disorder (ASD) often exhibit communication difficulties that may stem from basic auditory temporal integration impairment but also be aggravated by an audio-visual integration deficit, resulting in a lack of interest in face-to-face communication. This study addresses whether speech processing anomalies in young autistic children (mean age 3.09-year-old) are associated with alterations of audio-visual temporal integration.

Rapport in same and mixed neurotype groups of autistic and non-autistic adults

Autistic adults sometimes get along better with other autistic people compared to non-autistic people, but so far this has only been studied in two-person interactions. This study examined how well autistic and non-autistic people develop rapport in a group setting and whether rapport differs when group members share or do not share a diagnosis.

Social motor synchrony and interactive rapport in autistic, non-autistic, and mixed-neurotype dvads

During social interactions, people often mirror each other's movements and gestures, a process called synchrony. This synchrony helps foster a sense of connection, understanding, and ease in communication. While research suggests that autistic people may show less synchrony in their movements compared to non-autistic people, the implications of this difference for building rapport remain unclear. Specifically, it is unknown whether synchrony plays a similar role in rapport-building for autistic individuals as it does for non-autistic individuals, particularly in interactions with autistic versus non-autistic partners.

Study Summaries

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The diagnostic journey of autistic people: identity, relationships, adaptation and assimilation Autism Spectrum Disorder (ASD) is a lifelong condition characterised by significant difficulties in social communication and interaction. Furthermore, those diagnosed with ASD frequently demonstrate restricted and repetitive patterns of behaviours and differences in sensory processing (Martinez et al., 2024; Symons, 2021).

News

Autism assessment waiting times

As of December 2024, 212,964 people were waiting for an autism assessment in England, latest NHS data has revealed.

Restraint in Schools in England

After more than a decade campaigning on the misuse of restraint in schools along with family carer campaigners and others, we are pleased to share that the Department for Education have committed to:

- Introduce a legal requirement for schools to record every significant incident of use of force and report these incidents to the parents of the pupils involved, effective from September 2025
- Revise the Department for Education Guidance on the "Use of Force" with an emphasis on the need to minimise the need for all restrictive interventions by focussing on prevention and de-escalation strategies and data analysis.









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Premature mortality nine times more likely in young adults with learning disabilities New research on premature mortality found that adults with learning disabilities over 25 years old are dying, on average, 15 years younger than adults in the general population.

Poor NHS admin is harmful to people with a learning disability

Carers and patients with long-term health conditions are significantly more likely to experience issues with NHS admin and communication that impact their care, according to a new report from the King's Fund.

Constipation care at forefront of new health campaign

Ace Anglia, a people-led advocacy organisation working with people with learning disabilities and autistic people across Suffolk, have shared a new video highlighting the dangers of poor constipation care.

New campaign to halt closure of village communities for people with a learning disability Group or village communities for people with learning disabilities and autistic people are in danger of closing, and new ones cannot be developed due to a one-sentence loophole in guidance from the Care Quality Commission (CQC).

DPO Forum expresses "serious concerns" about direction of disability benefits green paper The Disabled People's Organisation (DPO) Forum says it is "deeply worried" about the direction of some of the benefits proposals for the upcoming Work Capability Assessment (WCA) and Personal Independence Payment (PIP) Green Paper.



