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Studies

quality of life

Don't assume, ask! A focus group study on end-of-life care planning with people with intellectual disabilities from minoritised ethnic groups

People with intellectual disabilities are less likely to have access to palliative care, and the evidence shows that their deaths are often unanticipated, unplanned for, and poorly managed. Within the general population, people from minoritised ethnic groups are underrepresented within palliative care services. End-of-life care planning with people with intellectual disabilities from minoritised ethnic groups may be a way to address these issues. There is a huge gap in the evidence regarding intersectionality of intellectual disability and ethnicity within end-of-life care planning.

Autism spectrum disorder, social anxiety and obsessive-compulsive disorders: beyond the comorbidity

Autism spectrum disorder (ASD) is characterized by high rates of comorbidity with other mental disorders, including anxiety disorders and obsessive-compulsive disorder. Beyond a mere concept of comorbidity, recent literature is speculating the existence of a neurodevelopmental nature of such mental disorders. The aim of the study is to investigate the distribution of socialphobic, obsessive-compulsive and panic-agoraphobic traits within a sample of individuals with ASD, social anxiety disorder (SAD), obsessive-compulsive disorder (OCD) and panic disorder (PD).

Relationship between social anxiety and separation anxiety symptoms with insistence on sameness with the mediating role of sensory hypersensitivity

Autism spectrum disorder (ASD) is characterized by impairments in social communication and interaction, restricted and repetitive patterns of behavior, and sensory processing abnormalities. These core features are often accompanied by comorbid anxiety disorders. However, the sequence and mechanisms of these associations warrant further investigation.

Caregivers' experience of having a child with Down syndrome: a meta-synthesis This study aimed to integrate the experiences of caregivers of children with Down syndrome during the care process and understand their feelings and needs.

The COVID-19 pandemic's impact on UK social workers working with people with learning disabilities: A mixed methods study

The impact of the COVID-19 pandemic on the health and wellbeing of social workers working with people with learning disabilities has not been fully explored. This paper reports findings from a large United Kingdom study that surveyed health and care workers in six phases of the pandemic and shortly thereafter (2020-23) relating to 310 social workers who worked with people with learning disabilities.

Early Intervention for Children With Developmental Disabilities and Their Families via Telehealth: Systematic Review

Early intervention during the first 3 years of life is crucial for children with developmental disabilities to optimize developmental outcomes. However, access to such services is often limited by geographical distance and resource constraints. Telehealth can be part of a solution for overcoming these barriers, enabling the delivery of early intervention services. However, a comprehensive understanding of the efficacy and implementation of telehealth in early interventions remains elusive, particularly for children aged 0-3 years.











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How can we make therapy better for autistic adults? Autistic adults' ratings of helpfulness of adaptations to therapy

Autistic people are at elevated risk of mental health conditions and experience significant barriers to effective support. While adaptations to therapy for autistic people have been proposed by clinicians, there is limited research on how helpful autistic people themselves rate these. We aimed to address this gap.

"They Don't Understand People With Learning Disabilities": Exploring the Experiences of People With Intellectual Disabilities Undergoing Welfare Assessments

The Welfare Reform Act (2012) has been criticised for harming claimants, particularly through functional assessments. Although many people with intellectual disabilities in the UK receive welfare benefits, their experiences of undergoing functional assessments are under-researched.

The Meaning of Ageing and the Educational Intervention "Good Life in Old Age": An Ethnographic Study Reflecting the Perspective of Older Adults with Mild Intellectual Disability Older adults with intellectual disabilities are not adequately prepared for ageing and show anxiety and uncertainty regarding the future. Therefore, the two-year educational intervention "Good Life in Old Age" was implemented to improve their understanding of ageing and enhance their well-being. This study aimed to explore the meaning of ageing during and after the intervention from the perspective of older adults with mild intellectual disability.

<u>'It Feels Very Weird and Normal at the Same Time': Sibling Perceptions of Their Relationships With an Autistic Brother or Sister With Complex Care Needs</u>

The impact of having a disabled brother or sister on siblings' psychological well-being and sibling relationships has been the subject of several research studies. However, research which focuses on the relationship between siblings and their autistic brother or sister with an intellectual disability and complex care needs is rare.

<u>Migraine and its major subtypes – with and without aura are associated with polygenic scores</u> for autism

Individuals with autism spectrum disorder (ASD) experience a wide array of neurological, psychiatric and medical comorbidities, yet little attention has been given to the potential link between ASD and migraine, one of the most prevalent neurological disorders worldwide. This study aimed to investigate whether a genetic predisposition for ASD is linked to migraine and its major subtypes, with and without aura.

Atypical implicit and explicit sense of agency in autism: A complete characterization using the cue integration approach

There exist indications that sense of agency (SoA), the experience of being the cause of one's own actions and actions' outcomes, is altered in autism. However, no studies in autism have simultaneously investigated the integration mechanisms underpinning both implicit and explicit SoA, the two levels of agency proposed by the innovative cue integration approach.

"A space to be myself": Music and self-determination in the lives of autistic adults

Despite many decades of academic interest in music and autism, we know little about what music means to autistic adults and how they experience it. The few existing studies lack a common theoretical basis and are therefore difficult to compare and integrate. To address this gap, we investigated whether Self-Determination Theory can be used as a common framework for understanding the functions of music as experienced by autistic adults.











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Misunderstood, excluded, and othered: Lay constructions of autistic women

This qualitative investigation explored lay constructions of autistic women, a group that has been invisible from the making of "autism," as it is constructed by society.

<u>Integrating New Instructional Assistive Technology to Support Academic and Behavioural</u> Instruction for Students with Learning Disabilities

Assistive Technology can be a highly effective tool in supporting students with Learning Disabilities (LD) in addressing foundational academic skill gaps as part of academic and behavioural one-to-one instruction. However, there are barriers to administrators wanting to equip in-service educators to integrate assistive technology into special education contexts, such as in-service educators' technology acceptance and the need for effective in-service training.

<u>Learning from the community: iterative co-production of a programme to support the development of attention, regulation and thinking skills in toddlers at elevated likelihood of autism or ADHD</u>

Children showing many autistic traits, or who have a close family member on the autism spectrum or having ADHD, are more likely than average to struggle with attention, regulation and thinking skills. This may lead to difficulties with mental health and independent living in later life. We aimed to create a parent-toddler programme that would help children with a connection to autism or ADHD to thrive, without pressuring them to act in a certain way.

<u>Pragmatic performance</u>, its relationship with symptom severity, and early clinical predictors of pragmatics in 5 ~ 6-year-old children with autism spectrum disorder

Pragmatic language refers to using spoken language to convey messages effectively across diverse social communication contexts. However, minimal longitudinal research has focused on defining early predictors of pragmatic development in children with autism spectrum disorder (ASD).

E-Learning

Foundation Programme Update January - The Mental Capacity Act

The Mental Capacity Act (MCA) and Deprivation of Liberty (DoLs) are central to inpatient care. The MCA protects the rights of vulnerable people and this group of sessions cover topics such as assessing capacity, consent, patient autonomy and safeguarding.

Events

A FREE PBS support event – the Northern Powerhouse

The Northern Powerhouse is a collaboration between Greater Manchester Positive Behaviour Support Community of Practice and Cheshire and Merseyside Positive Behaviour Support Community of Practice.

How to improve adult social care for seldom-heard groups

Social care aims to improve the lives of people who need help in their daily living. It includes personal care, safeguarding and end-of-life care. This work, and the groups receiving care, can go unnoticed by society. Adults experiencing homelessness, those with learning disabilities and people living with dementia are some of the least heard groups.











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<u>Upcoming webinar: Addressing the health inequalities experienced by people with a learning</u> disability from Black, Asian and minoritised ethnic backgrounds

This presentation from Dr Jahan Foster Zabit of the Race Equality Foundation will explore the evidence related to poorer experiences and outcomes for people with a learning disability from Black, Asian and minoritised ethnic backgrounds and share findings from collaborative work between the Race Equality Foundation and Learning Disability England on improving access to and take-up of annual health checks.

Podcasts

The financial time bomb facing special educational needs - podcast

Richard Adams reports on the Send funding cliff edge affecting children and their development.

Blogs

"My goal is to learn as much as I can from other countries"

Steven Chapman, Self-Advocate and Co-Chair of the Board at Bemix, talks self-advocacy and building international connections...

News

New SCIE guidance to help tackle inequalities for people with learning disabilities and autistic people

Today, the Social Care Institute for Excellence (SCIE) has launched a new best practice resource for the adult social care workforce: 'Tackling inequalities in care for people with learning disabilities and autistic people'.

A Constant Fight report launch

Our charity has published a new report which highlights the fights and waits autistic people face to get support. More than 2,000 campaigners have joined us to call for the new Government to tackle inequalities faced by autistic people.

Autistic people face constant fight for health and social care support

Autistic people are bearing the brunt of a broken system and face a constant fight for health and social care support, according to a new report from the National Autistic Society.

Number of autistic people in mental health hospitals: latest data

The latest monthly Assuring Transformation NHS Digital data shows that in December 2024:

- In total 2,050 autistic people and people with a learning disability are in inpatient mental health hospitals in England
- 1,430 (70%) of these people are autistic
- There are 210 under 18s in inpatient units that are autistic or have a learning disability. Of these, 98% are autistic.

My brother is minimally verbal. He taught me that language is far more than mere words

The sound artist Ruby Colley, whose brother is non-speaking, has created a touching reminder that people can express themselves in other ways.











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Mencap creates Easy Read NHS 10-year plan consultation questionnaire

Mencap has created an Easy Read version of the NHS 10-year plan consultation questionnaire to help people with a learning disability get involved and have their say in the consultation on the future of the NHS in England.

Lords continues detailed check of Mental Health Bill

Members of the House of Lords resume their line by line scrutiny of the Mental Health Bill in committee stage on Monday 27 January.

Government has no financial solution to end SEND crisis, new report finds

A damning new report from the Public Accounts Committee (PAC) has highlighted a special educational needs and disabilities (SEND) system in disarray, which is failing the families who need it and putting almost half of all councils in England in danger of effective bankruptcy within 15 months.

Our response to the Public Accounts Committee report on SEND

Our charity has responded to a new report published today by the Public Accounts Committee on support for children and young people in the SEND system.

SEND emergency: Unviable system will end in lost generation of children without reform

A lost generation of children could leave school without having received the help they need. In its report on support for children and young people with special educational needs (SEN), the Public Accounts Committee (PAC) today issues an urgent call for Government to take action to improve a system which is failing the families who need it, and putting almost half of all councils in England in danger of effective bankruptcy within 15 months.

"A new costed plan for the SEND system is urgently needed," say psychologists

A new report from the Public Accounts Committee has warned the system for children with special educational needs and disabilities (SEND) is "unviable" and will result in a "lost generation of children". Responding to the findings, Dr Helena Bunn, chair of the Division of Educational and Child Psychology at the British Psychological Society.

X marks the spot in search for autism variants

Genetic variants on the X chromosome, including those in the gene DDX53, contribute to autism's gender imbalance, two new studies suggest.









