challenging behaviour Disabilities an Mersey Care ing research health information carers **NHS Foundation Trust** Asperger Syndrome mental capacity intellectual disabilities

24 April 2024

Studies

quality of life

Identification and support of autistic individuals within the UK Criminal Justice System: a practical approach based upon professional consensus with input from lived experience Autism spectrum disorder (hereafter referred to as autism) is characterised by difficulties with (i) social communication, social interaction, and (ii) restricted and repetitive interests and behaviours. Estimates of autism prevalence within the criminal justice system (CJS) vary considerably, but there is evidence to suggest that the condition can be missed or misidentified within this population. Autism has implications for an individual's journey through the CJS, from police questioning and engagement in court proceedings through to risk assessment, formulation, therapeutic approaches, engagement with support services, and long-term social and legal outcomes.

Kidney and urogenital abnormalities in Down syndrome: a meta-analysis

Reviews on Down syndrome do not or only marginally address the issue of kidney and urogenital tract abnormalities, and lower urinary tract dysfunctions. Hence, we performed a meta-analysis of the literature.

Identifying barriers and facilitators to primary care practitioners implementing health assessments for people with intellectual disability: a Theoretical Domains Framework-informed scoping review

People with intellectual disability experience poorer health outcomes compared with the general population, partly due to the difficulties of accessing preventive care in primary care settings. There is good evidence that structured annual health assessments can enhance quality of care for people with intellectual disability, and their use has become recommended policy in several high-income countries. However, uptake remains low. The Theoretical Domains Framework (TDF) offers a conceptual structure for understanding barriers to implementation and has been usefully applied to inform implementation of health assessments for other highneed groups, but not for people with intellectual disability.

Comparison of self-esteem and quality of life in 8-12-year-old children with ADHD with and without learning disorders

Attention Deficit/Hyperactivity Disorder (ADHD) is one of the most common disorders in schoolaged children. Learning disorder (LD) is also one of the most important psychiatric disorders in children, which can often be associated with ADHD. In this study, we sought to compare selfesteem and quality of life in 8 to 12-year-old children with attention deficit/hyperactivity disorder with and without co-occurring learning disorders in order to emphasize the importance of attention and diagnosis in children with ADHD.

The experiences of Black African parents on partnership: Working with education professionals in the English special education needs and disability system

Reforms to special education policy in England have emphasised the importance of parents being involved in decision-making about their child's education and greater control over their child's support. This study's research questions investigated four Black African parents of children with special educational needs and disability (SEND) living in England and their experiences of working in partnership with education professionals to support their children, as well as exploring the barriers to effective partnership between Black African parents and education professionals.









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"A perfect storm": Autistic experiences of menopause and midlife

Previous research indicates that menopause can be an extremely difficult transition for some autistic people. This study asks how autistic people experience menopause and how they can better access services, support and information; autistic Community Research Associates played an important role in each stage of the research.

Camouflaging, not sensory processing or autistic identity, predicts eating disorder symptoms in autistic adults

The objective of this study was to explore the role that Autistic identity, sensory processing and camouflaging behaviours have on eating disorder symptomology in Autistic adults. Previous research has focused on cognitive and sensory factors to explain the association between autism and eating disorders, but the roles of social identity and camouflaging are yet to be explored.

Preeclampsia Onset, Days to Delivery, and Autism Spectrum Disorders in Offspring: Clinical Birth Cohort Study

Maternal preeclampsia is associated with a risk of autism spectrum disorders (ASD) in offspring. However, it is unknown whether the increased ASD risk associated with preeclampsia is due to preeclampsia onset or clinical management of preeclampsia after onset, as clinical expectant management of preeclampsia allows pregnant women with this complication to remain pregnant for potentially weeks depending on the onset and severity. Identifying the risk associated with preeclampsia onset and exposure provides evidence to support the care of high-risk pregnancies and reduce adverse effects on offspring.

Guidance

Dynamic Support Register (DSR) Care Education and Treatment Review (CETR) young person guides

A set of young people Dynamic Support Register (DSR) and Care Education and Treatment Review (CETR) guides for Autistic young people aged between 16 and 25 years. These leaflets are aimed to empower young people to better understand the process and benefits of deciding whether to be on a DSR, have a C(E)TR and be actively involved in this process.

Culture of care standards for mental health inpatient services

The following co-produced guidance sets out the culture of care everyone, including people who use services, families, carers and staff, want to experience in mental health inpatient settings, and supports providers to realise this. The standards apply to all NHS-funded mental health inpatient service types, including those for people with a learning disability and autistic people, as well as specialised mental health inpatient services such as mother and baby units, secure services, and children and young people's mental health inpatient services.

Blogs

All In This Together – A blog by Sarah Maguire

Sarah is the CEO of Choice Support, a social care Community Benefit Society that creates opportunities for happiness for people with learning disabilities, mental health needs and autistic people.











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Is autism being overdiagnosed?

This is one of the questions I am most often asked in my role as Autism Champion, by both psychiatry colleagues and laypeople. Most people have a sense that 'there is more autism about' these days. It is now rare to find someone who doesn't have a friend or relative affected by autism. A recent article in the Guardian newspaper highlighted the issue of a large rise in autism diagnoses in the UK. But does this mean that autism is being overdiagnosed?

News

New CETR and DSR Guides for Autistic Young People

NHS England has published new guides on Dynamic Support Registers (DSRs) and Care, Education, and Treatment reviews (CETRs) for autistic young people. The guides are intended to empower young people to decide whether or not DSRs and CETRs are right for them.

Government misses target to reduce number of people with a learning disability and autistic people in inpatient units by 50%

NHS Digital statistics confirm that the government has missed its target to reduce the number of people with a learning disability and autistic people detained in inpatient units by 50% - with more than 2000 people still stuck in these units, there need to be concrete actions to achieve meaningful change.

'People like Connor are still left to die in squalor': the truth, joy and tragedy behind Laughing Boy

A decade after her autistic son Connor Sparrowhawk died in a specialist NHS facility, Sara Ryan's campaign to reveal the truth about what happened is coming to the stage.

New report on supporting siblings in school

Three quarters of siblings who have a brother or sister with a disability, special educational need (SEND) or long-term health condition do not receive any extra support from school.

New rugby scheme launched for people with a learning disability

A learning disability rugby programme has been launched by the Newcastle Rugby Foundation aimed at empowering individuals with learning disabilities and giving them a chance to become a rugby player.

MP visits SeeAbility's new 'Easy Eye Care Service' scheme

SeeAbility has launched a new 'Easy Eye Care Service' scheme where accredited opticians are funded by the NHS to provide longer or multiple appointments, along with any adjustments that people with learning disabilities or autism may need.

New project to highlight the work challenges unpaid carers face

A new project has been launched to examine the challenges unpaid carers face when applying for jobs in the workplace and also what carer-friendly workplaces should look like.

Getting Seen, Getting Heard, Getting Involved for Good Support

An Update from Gary and Mary on the Houses of Parliament Reception to Launch the Future of Care 5 Report written by the Social Care APPG in March 2024.











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<u>MPs to hold a debate on the Buckland Review of Autism Employment</u> On Thursday 25 April, MPs will hold a debate on the Buckland Review of Autism Employment.

AAC app update aims to boost communication access

In its latest effort to bridge communication gaps, Spoken has announced an update to its augmentative and alternative communication (AAC) app, aimed at providing adults with speech impairments a more intuitive and inclusive tool for expression.

Autism makes travel a challenge. Here's how I learned to cope

Busy places and unexpected events used to send me into meltdown on holiday. An autism diagnosis helped me to adapt my plans and rediscover the joy of travelling.





