

Quality Network for Learning Disability Services

Annual Forum 2022

Tuesday 6 December



Working with Co-morbidities

Programme

9:30 Welcome and Introductions

Janet Seale, QNLD Carer Representative

Dr Kiran Purandare, QNLD Accreditation Committee & Advisory Group Chair & Consultant Psychiatrist, Central & North West London NHS Foundation Trust

9:40 Through the looking glass - Epilepsy and intellectual disabilities the last decade

Professor Rohit Shankar MBE, Professor in Neuropsychiatry/Clinical Director – Adult Learning Disability services/Consultant in Adult Developmental Neuropsychiatry, Cornwall Partnership NHS Foundation Trust

10:10 QNLD Project Update

Amy Colwill, QNLD Programme Manager, Izzy Sanders & Tianna Stephens, QNLD Project Officers

10:30 Co-morbidity with Neurodevelopmental disorders

Dr Deepak N Swamy, Specialist Psychiatrist in Autism & Neurodevelopment, Sheffield Adult Autism & Neurodevelopmental Service (SAANS), Sheffield Health & Social Care NHS Foundation Trust

11:10 Break

11:25 Networking

Attendees will have the opportunity to network with colleagues in break out rooms.

11:40 Working with primary care to provide joint annual physical health checks for people with learning disabilities

Dr Nathalie Leyland, Consultant Psychiatrist, Avon and Wiltshire MH Partnership NHS Trust

Dr Chetal Sheth, General Practitioner (GP) Millstream Medical Practice, Salisbury

12:15 Lunch Break

12:50 Co-production of a Gold Standard Environment Audit – a focus on the environmental needs of people with Autism when admitted to hospital

Sylvia Dubarry-Lassalle, Regional Director of Occupational Therapy, Caragh Allbright, Clinical Lead Speech and Language Therapist for Learning Disability and Autism, Rebecca Griffiths Regional Lead Occupational Therapist & Flo, Patient Contributor Cygnet Health Care LTD



Programme

13:30 Managing constipation in people with learning disability

Dr Richard Laugharne, Emeritus Consultant Psychiatrist, Cornwall Partnership Trust and CIDER (Cornwall Intellectual Disability Equitable Research)

14:00 Trauma Informed Care

Dr Vicky Lauté, Clinical Psychologist, Intensive Support Service, Surrey & Borders Partnership NHS Foundation Trust

14:30 Break

14:45 Health Factors and co-morbidities within Learning Disabled and Autism populations

Matt Edgar and Owen Bruce, Operational Team Managers, Greater Manchester Specialist Support Team

15:15 Advocacy for Autistic People in Mental Health Inpatient Settings

Sarah Jackson, Consultant Nurse, Associate Director of Nursing Autism Clinical Pathway Lead and Trainee Approved Clinician, Lancashire & South Cumbria NHS Foundation Trust & Ellie Bradley, Advocacy Manager, Advocacy Focus

15:45 Closing remarks

Janet Seale, QNLD Carer Representative

Dr Kiran Purandare, QNLD Accreditation Committee & Advisory Group Chair & Consultant Psychiatrist, Central & North West London NHS Foundation Trust

16:00 Close



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Using the hashtag #QNLD

Advocacy for Autistic People in Mental Health Inpatient Settings

Sarah Jackson and Ellie Bradley

Since April this year, Advocacy Focus have been running a pilot project across Lancashire and South Cumbria NHS Foundation Trust mental health inpatient settings, designed primarily to provide advocacy support to autistic Informal inpatients - who are not ordinarily legally entitled to this support, and also to engage with autistic people who are detained under a section of the Mental Health Act, to learn about their experiences of inpatient care.

Lancashire and South Cumbria NHS Foundation Trust sourced funding for this project through the NHS England National Learning Disability and Autism Quality Programme. This has enabled a deeper understanding of the issues faced by autistic people in mental health inpatient settings, and to consider how processes, environments and support can be reasonably adjusted to meet their needs. This project has begun to gather valuable data which will hopefully aid in making strategic changes needed to improve the experience of mental health care for autistic people across LSCft mental health inpatient settings. Some great outcomes have already been achieved, supporting autistic people to challenge where appropriate and supporting them to be heard by professionals.

This session aims to explore our findings to date and most importantly share some of the views of the people with lived experience around how they feel their care and treatment is, their perception and use of advocacy, along with how things can be changed to improve the quality of life of autistic people in mental health inpatient settings.

Co-morbidity with Neurodevelopmental disorders

Dr Deepak N Swamy

Sheffield Adult Autism and Neurodevelopmental Service (SAANS) is a regional neurodevelopmental diagnostic service providing assessments to both Sheffield and Regional patients. This will be a presentation on Comorbidity with Neurodevelopmental disorders. It will focus mainly on ASD, its core features, summary of assessment, interventions and management. Then it will be about Co-morbid conditions with ASD (mainly BPD and ASD) and its differentiating features. Then it will be about ADHD, its core features, summary of management. Then it will be about Co-morbid conditions with ADHD (mainly EUPD and ADHD, Anti-social PD and ADHD, ASD and ADHD) and its differentiating features. The presentation will also briefly touch upon Executive dysfunction, improving working memory and sensory deficits.

Managing constipation in people with learning disability

Dr Richard Laugharne, Emeritus Consultant Psychiatrist, Cornwall Partnership Trust and CIDER (Cornwall Intellectual Disability Equitable Research)

Constipation is a significant problem for people with learning disabilities (PwID). Depending on the measure of constipation, 33-50% of PwID have constipation and in a twelve month period 25% of PwID are prescribed regular laxatives compared to 0.1% of the general population.

Factors contributing to this increased risk of constipation include:

- 1. Neurological impairments in bowel functioning.
- 2.Difficulties communicating pain and other symptoms.
- 3.Reduced physical mobility due to disability or lack of exercise.
- 4.Poor diet lacking in fibre.
- 5.Poor fluid intake.

6. Side effects of medication including antiepileptics, antipsychotics and anticholinergics.

With NHS England, we have completed a piece of qualitative research on the views of parents of children with ID on how their bowel health is managed.

We have published a literature review on this area and from the published literature developed a constipation questionnaire. This has been piloted for at least 160 people in Cornwall, Haringey, Hertfordshire and Devon. We will present the questionnaire and early results from the survey. If in a workshop format, we can discuss how this questionnaire can be used for local services to offer individualised bowel care plans.

We have also surveyed the care of PwID who were admitted to the general hospitals in Devon and Cornwall due to complications of constipation to review any lessons that might be learned from this data.

We hope to develop guidelines on the management of constipation in PwID from previous research and also new research emerging. We will also discuss good prescribing practice for laxatives in constipation. If in a workshop we can discuss the experience of the attending psychiatrists to develop these guidelines further.

Trauma Informed Care

Dr Vicky Lauté, Clinical Psychologist, Intensive Support Service, Surrey & Borders Partnership NHS Foundation Trust

This presentation will offer a definition of relational (or complex) trauma. The current evidence base will be briefly outlined. The rationale for applying this way of working in services for people with learning disabilities will be described. The model adopted in an Intensive Support Service and a wider NHS Trust Directorate will be shared. Progress, challenges and hopes for the future will be included.

Health factors and co-morbidities within Learning Disabled and Autism populations

Matthew Edgar and Owen Bruce, Operational Team Managers, Greater Manchester Specialist Support Team

Greater Manchester Specialist Support team is a Learning Disability and Autism community service. The referral criteria include those at risk of placement breakdown, potential for criminal justice pathways and supporting transition from prisons or long-term hospital care back into the community. In covering the 10 boroughs of Greater Manchester, GM SST holds a unique perspective on Learning Disabilities and Autism provision and niche complex cases across the area.

The people we work with at SST present with a wide breadth of both physical and mental health factors in addition to their Autism and Learning Disability diagnosis. Research has shown the physical health inequalities in people with Learning Disabilities, who present with a disproportionate level of physical health factors. This creates a complex picture, in which identifying and distinguishing the factors influencing different behaviours of concern can be difficult. These difficulties can be further intensified when individuals present in crisis or when the systems around the individual are struggling to provide support.

The case studies presented will outline the difficulties in distinguishing between physical and mental health factors in individuals with Autism and/or Learning Disabilities with co-morbidities. Demonstrating the necessity for care teams to maintain an open mind when generating hypothesis around an individual's presentation, and the particular importance when people have limited communication skills. As well as highlighting issues around diagnostic overshadowing and the reliance on care teams and professionals to identify and communicate issues across wider multi-disciplinary teams. Ultimately stressing the significance of identifying, understanding, and treating physical health factors as central in understanding peoples needs and developing treatment plans. Through this presentation we will share examples of SST interventions and how as an MDT, alongside community teams, we have approached complex cases with multiple co-morbidities present and stabilised clients' presentations.

Through the looking glass - Epilepsy and intellectual disabilities the last decade

Professor Rohit Shankar MBE

An update on the developing understanding of the link between epilepsy and ID, the concerns, and challenges in patient management and service delivery. The developing solutions will be highlighted.

Working with primary care to provide joint annual physical health checks for people with learning disabilities

Dr Nathalie Leyland and Dr Chetal Sheth

As psychiatrists in learning disability, we are painfully aware of the health inequalities and premature mortality suffered by those for whom we work. In an effort to address this, for the last five years, I have been working directly with primary care colleagues in South Wiltshire to provide a joint annual health check. Along with GP Dr Chet Sheth, who proposed this innovative practice, I would like to share our model, our positive outcomes, and our reflections.

Co-production of a Gold Standard Environment Audit – a focus on the environmental needs of people with Autism when admitted to hospital

Sylvia Dubarry-Lassalle, Caragh Allbright, Rebecca Griffiths and Flo

Based on national guidelines, including the South West Yorkshire NHS Trust's "Checklist for Autism Friendly Environments", NICE guidelines and information from the National Autistic Society website, an audit was coproduced by a patient with Autism, her Occupational Therapist and the Speech and Language Therapist within a small hospital setting for people with Learning Disabilities.

The need for the audit was identified by the Learning Disability and Autism (LDA) Clinical Steering Group within Cygnet. This came about after a review of our ability to engage people in meaningful activity on the back of the Norfolk Safeguarding review, commissioned towards the end of 2022, in which 3 people died within an in-patient setting. It was then highlighted how important the environment is to enable people to engage with others, have meaningful experiences and progress in their recovery.

The audit was co-produced to provide an accurate assessment of Cygnet's in-patient LDA environments, based on what patients say they need. In her own words, the patient involved in this stated: 'Co-production means that I have a voice in my care and my voice is valued and considered just as expert as a doctor. A patient is after all an expert on their own experience. It has allowed staff to work with me to manage the difficulties I have rather than making assumptions about what I need which has ultimately lead to me receiving better care'.

By addressing the sensory and communication aspects of the environment, together with assessing staff knowledge and skills, Cygnet was able to evaluate all services that provide bespoke care for people with LDA and create action plans to address their needs.

Speaker details have been provided where a short speaker biography was made available.

Professor Rohit Shankar MBE (Through the looking glass - Epilepsy and intellectual disabilities the last decade)

https://www.plymouth.ac.uk/staff/rohit-shankar

Rohit is a professor in Neuropsychiatry with University of Plymouth Medical School and director of its Cornwall Intellectual Disability Equitable Research (CIDER) unit https://www.plymouth.ac.uk/research/cidercornwall-intellectual-disability-equitable-research. He is a consultant in developmental neuropsychiatry and clinical director for the Cornwall adult intellectual disability services. Awarded an MBE (2018) for services to the learning disability community he has national/international awards including the Royal College of Psychiatrists (RCPsych) Intellectual disabilities team of the year (2021), British Medical Journal (BMJ) awards for mental health (2020), Education (2019) Neurology (2016), Innovation (highly commended-2017), ILAE Epileptic Disorders best paper (2017) and Epilepsy Foundation America SUDEP Challenge (2016). He is the chair of the RCPsych Southwest England division, the vice-chair of the Intellectual disability faculty of the RCPsych and lead of the Cochrane update for pharmacological and non-pharmacological interventions in people with epilepsy and intellectual disabilities. He is on the NICE epilepsy panel, National confidential inquiry for deaths in epilepsy, the global International League Against Epilepsy (ILAE) commission for inclusion and diversity and the ILAE task force for neurodevelopmental disorders. His interests are in co-producing with patients' translational clinical research in neurodevelopmental/neuropsychiatric disorders, risk management, and health technology. In the last 3 years he has been involved in over 10 million pounds worth of grant funding either as principal investigator or co-applicant. He has over 200 index-linked publications/book-chapters and led/contributed to various national reports with over 90% as first/last and/or corresponding author. Publications are on https://orcid.org/0000- 0002-1183-6933 & https://www.plymouth.ac.uk/staff/rohit-shankar

Dr Deepak N Swamy (Co-morbidity with Neurodevelopmental disorders)

Dr Deepak N Swamy is a Specialist Psychiatrist in Adult Autism and Neurodevelopment at Sheffield Adult Autism & Neurodevelopmental Service (SAANS), Sheffield Health & Social Care NHS Foundation Trust. SAANS is a regional neurodevelopmental diagnostic service providing assessments to both Sheffield and Regional patients. He has previously worked in Learning Disabilities service at Nottinghamshire. Apart from medical qualifications, he has additional qualifications in healthcare management, clinical research and medical education. He has special interests in neurodevelopmental disorders and physical healthcare management. He is a Honorary Senior Clinical Teacher, Faculty of Medicine, Dentistry and Health at University of Sheffield Medical School and has been involved in teaching a variety of professionals including medical students, Nursing students, Psychiatry Core and GP trainees. He has been a Mentor for Foundation Year doctors, Supervisor for ACP trainees, OSCE examiner for medical students and medical graduates seeking PG medical training in UK, NMP Supervisor for Nurses and Clinical Supervisor for Higher Trainees in Neurodevelopment as a special interest post. He also has various roles at RCPsych such as LD Faculty Representative, College Assessor, QNLD Peer Reviewer and QNLD Accreditation Committee LD Representative Member.

Dr Kiran Purandare (Co-chair)

Kiran works at the Kingswood Centre, an inpatient assessment and treatment unit for adults with ID in NW London as well as in the ID community team in Brent, NW London. He has an interest in teaching and research. He has been part of the QNLD for a long time and is currently Chair of the Advisory Group.

Dr Nathalie Leyland (Working with primary care to provide joint annual physical health checks for people with learning disabilities)

I have been working as the Consultant Psychiatrist in South Wiltshire Community Team for People with Learning Disabilities for almost seven years, following completing dual training in Learning Disability and Child and Adolescent Psychiatry.

Dr Chetal Sheth (Working with primary care to provide joint annual physical health checks for people with learning disabilities)

I have been a GP partner since 2008 in Salisbury.

My passion is medical entrepreneurship / redesign of clinical care to get the best outcomes for clinicians and patients – and have set up and run:

- A innovative learning disability pathway to improve the health of the most vulnerable in our society
- A Clinical decision support tool ardens which supports 4000 GP Practices providing up to date information to clinicians
- · Community heart failure service
- Walk In Centre
- Community Pharmacy
- Freedom to speak out service for healthcare

I have had different leadership roles locally in health care:

- Vice Chair of Wiltshire CCG
- Primary care Clinical Director

Sylvia Dubarry-Lassalle (Co-production of a Gold Standard Environment Audit – a focus on the environmental needs of people with Autism when admitted to hospital)

With 30 years' experience as an occupational therapist, I support and lead the occupational therapy departments across a range of hospital and residential home services within the South and London region in Cygnet. I also chair the Learning Disability and Autism Clinical Steering Group, supporting all specialist services within this client group to apply an evidence-based model of care, with agreed processes to ensure care is delivered effectively. My clinical background is working with people who have learning disabilities and autistic people.

Caragh Allbright (Co-production of a Gold Standard Environment Audit – a focus on the environmental needs of people with Autism when admitted to hospital)

Clinical Lead Speech and Language Therapist for Learning Disability and Autism at Cygnet Healthcare. My role allows me to work collaboratively to support and develop approaches that not only support the service user whilst in hospital but also their transition into a new home in the community.

Rebecca Griffiths (Co-production of a Gold Standard Environment Audit – a focus on the environmental needs of people with Autism when admitted to hospital)

Regional Lead Occupational Therapist for Learning Disability Hospitals within Cygnet Healthcare. Qualified as an OT in 2010 and have worked within various mental health and learning disability services since during this time.

Dr Richard Laugharne (Managing constipation in people with learning disability)

Richard Laugharne is a consultant psychiatrist who worked in general adult psychiatry for 22 years and for the last 2 years in ID psychiatry. He has been Lead for Mental Health Research in Cornwall for the last 14 years and is Deputy Clinical Director of the SW Clinical Research Network. He has worked with Professor Rohit Shankar in establishing the Cornwall Intellectual Disability Equitable Research (CIDER) Unit at Plymouth University School of Medicine. He has authored or co-authored over 60 papers. He has also been the Head of School of Psychiatry in the SW Peninsula leading postgraduate training in psychiatry.

Matt Edgar (Health Factors and co-morbidities within Learning Disabled and Autism populations)

Matt Edgar is a RNLD qualifying in 2004. Worked in low and medium secure services until 2010 then into the community for a year with the Forensic Support Service. Returned and worked in an individualized package of care before sometime in the independent sector, within an independent PICU before returning to the community in 2017 and commencing my current role in 2021.

Owen Bruce (Health Factors and co-morbidities within Learning Disabled and Autism populations)

Owen Bruce is an Assistant Psychologist who has been working with the Greater Manchester Specialist Support Team (SST) since 2020. Having previously worked in the charitable sector and in supported living, transitioned to psychology in 2019 completing studies at Manchester Metropolitan University. Within the SST he has established a research group to oversee and coordinate research within a frontline setting and help push learning from practice across GM.

The SST are an MDT of nurses, psychologists, assistant psychologists, speech and language therapists, social worker, occupational therapists, support workers and psychiatrist, who support people with a learning disability and or autism at risk of hospital admission, with discharge from hospital, at risk of contact with criminal justice agencies and the teams who support them, across the Greater Manchester footprint.

Dr Vicky Lauté (Trauma Informed Care)

I am a Principle Lead Clinical Psychologist, working in an Intensive Support Service for people with learning disabilities. This involves supporting people at risk of placement breakdown or hospital admission, as well as those who have been admitted to our inpatient assessment and treatment unit. I have obtained an Advanced Professional Diploma in Positive Behaviour Support. I have completed an AFT accredited Foundation level course in Family Interventions. I have also undergone a Teacher Training programme in Adapted Mindfulness-based Interventions. More recently, I have attended training with the UK Psychological Trauma Society and delivered training about Compassionate Leadership and Trauma Informed Care within my Trust.

Trauma informed services are developing in the NHS across all parts of the UK. When one of my colleagues started a Quality Improvement Project about Trauma Informed Care, I joined the team and found a natural synergy with my own hopes for service development, in terms of psychological interventions, staff wellbeing and partnership working. My presentation will summarise the journey we have been on within our Directorate and outline our hopes for the future.

Sarah Jackson (Advocacy for Autistic People in Mental Health Inpatient Settings)

I am a Principle Lead Clinical Psychologist, working in an Intensive Support Service for people with learning disabilities. This involves supporting people at risk of placement breakdown or hospital admission, as well as those who have been admitted to our inpatient assessment and treatment unit. I have obtained an Advanced Professional Diploma in Positive Behaviour Support. I have completed an AFT accredited Foundation level course in Family Interventions. I have also undergone a Teacher Training programme in Adapted Mindfulness-based Interventions. More recently, I have attended training with the UK Psychological Trauma Society and delivered training about Compassionate Leadership and Trauma Informed Care within my Trust.

Ellie Bradley (Advocacy for Autistic People in Mental Health Inpatient Settings)

Ellie has worked at Advocacy Focus for 4 and a half years and her previous work experience has been working with autistic children in schools as well as supporting adults with autism and learning disabilities in the community to live independently. Through this, Ellie gained a passion for person centred support and achieving the best outcomes for people and places great emphasis on empowering people to have control over their own lives. Ellie is a multi-skilled advocate working across the Mental Capacity Act, Mental Health and the Care Act.

Keep in touch

If you have any questions or would like to know more about the network **get in touch** with the QNLD project team on L.D@rcpsych.ac.uk

To be informed on project updates and activities please email 'Bulletin' to subscribe to the QNLD fortnightly bulletin.



Thank you for attending the QNLD Annual Forum. Please share your thoughts about the event by filling out the <u>short feedback form</u>.

We will use your feedback to shape future QNLD events.

