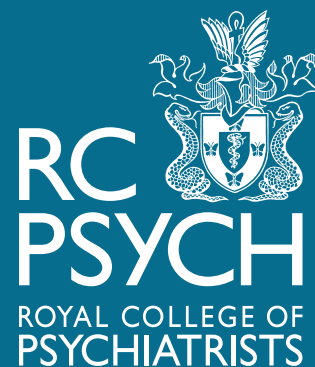


# Faculty of Psychiatry of Intellectual Disability Newsletter

January 2025



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## Editorial

Happy New Year and welcome to the Intellectual Disability Psychiatry Faculty Newsletter.

We are excited to bring you an edition packed full of a variety of topics, starting with a message from the chair, Dr. Indermeet Sawhney, whose guidance and inspiration are essential to the revival and momentum of this newsletter.

We had the privilege of conducting a key interview with the National Clinical Director for the NHSE Learning Disability and Autism Programme and former Faculty Chair, Dr Ken Courtenay. In this wide-ranging article (which we sadly had to abridge), he discussed his personal and professional capacities, his roles and participation in the ID Faculty and NHS England, as well as his outlook for the future of the faculty.

We received updates from the speciality trainee representatives, Dr Elizabeth Anslow and Dr Abigail Swift. As Abi's time as the national trainee representative comes to an end, we want to take this opportunity to thank her for her representation and leadership during her tenure as the Speciality Trainee representative on the faculty executive committee.

Dr Khodabux, an ST6 trainee in Leicestershire partnership trust, shared her Alec Shapiro presentation prize-winning article on Unravelling Safety Issues in Learning Disability Mental Health Care: Insights from Incident Investigations. Similarly, Dr. Louise Howitt shares insights from her experience with the innovative work that earned her the prestigious Gregory O'Brien Travel Fellowship. We also hear from our Psych star, Megan Grainer, a 4th-year medical student at Imperial College London. She is indeed a budding star, and we look forward to welcoming her into the fold in the near future.

We include valuable reflections from two fourth-year medical students: Meghna Nair from the University of Leeds, who shared her experience and thoughts on the use of psychotropic medications in individuals with ID, and Aleena Nauman from the University of Glasgow, who

discussed the importance of communication skills, particularly in the context of intellectual disability (ID) psychiatry.

DNA (Did Not Attend) is a significant issue that drains resources and presents both clinical and economic challenges, especially among patients with ID. Dr Heena Mistry and her team conducted an audit followed by a quality improvement initiative to address this problem within their team in Leeds. In the neighbouring Southwest Yorkshire NHS Trust, Dr Michael and his supervisor, Dr John, conducted a Quality Improvement Project focused on healthcare standards for the ID population in their area. This text discusses the challenges they faced and their collaborative work with GP colleagues to enhance the annual physical health reviews for patients with ID.

In our conference watch, Dr. Megan Viegas and Dr. Hannah Newman share valuable insights and inspiration from their experiences at the ID Faculty Annual Conference. Whilst in the media watch section, Dr Barbara Veras, a CT3 trainee at the St George Mental Health Trust, shares her thoughts on the representation of individuals with ID in the popular TV series "Love on the Spectrum."

We were pleasantly surprised by the wide range and high quality of submissions in response to our calls, and we would like to express our gratitude to all our contributors. We hope some of you are inspired to continue writing for us as we look forward to evolving ideas that will keep the newsletter contemporary, relevant, and a valuable addition to your routine reading list.

Finally, we extend our thanks to the Editorial Committee and Kitti Kottasz, whose significant contributions of time, attention, and effort greatly enhanced this publication. We hope you enjoy reading these articles as much as we enjoyed compiling them.

**Maruf and Sonya**  
Lead Co-Editors



## Chair's Message

**Dr Inder Sawhney**  
**Chair of ID Faculty**



Dear Colleagues,

Wishing you all a very happy new year! Hope Santa was generous and you all had some relaxing time during the festive period with your family and friends. With things back to a routine, most of you would have returned to work with batteries charged and renewed vigour for the new year.

Last year seems to have flown by! Here is the summary of the Faculty's activities in the last few months:

### National

As most of you will be aware the Government presented a Mental Health Bill to Parliament last year and this is now proceeding to the committee stage, beginning in the House of Lords next week. Within the Faculty we have worked closely with the College and DHSC raising concerns about the unintended and negative consequences of these proposed changes on people with a learning disability as well as their families and carers. We remain committed in our quest to influence and suggest proactive amendments to these proposals to mitigate some of the unintended consequences.

If you recall, in the summer last year the Faculty had responded to Baroness Hollins's report and recommendations on Independent Care (Education) and Treatment Reviews where we welcomed and agreed with some recommendations whilst expressed concerns and disagreed with others in the report. Subsequently we had a roundtable discussion with Baroness Hollins and her team to discuss the report and the College response. We as a Faculty have renewed our commitment to reduce restrictive practice and improve clinical practice in this context.

Last year following Lord Darzi's independent review of the NHS the Faculty has engaged with the Learning Disability Policy group and put forward proposals to tackle the health inequalities faced by people with a learning disability. The development of the NHS 10-year plan is a great opportunity to improve the lives of the very vulnerable population we serve.

### GMC Dual CCT

Delighted the hard work of our colleagues has born fruit and we had the great news about the GMC approving the dual CCT in Psychiatry of ID and Forensic Psychiatry. This is going to be an excellent opportunity for trainees to train in 2 specialties over 5 years and improve care for offenders with ID.

### College

We have just concluded our work with our colleagues in the British Psychological Society on updating the guidance on dementia in people with Intellectual Disabilities, which we hope to launch in the summer of this year; will keep you posted. Massive thank to our colleagues particularly: Dr Shahid Zaman & Prof Andre Strydom for their hard work and contribution to this report.

We are also working on the update for the Challenging Behaviour in ID guidelines, again jointly with the British Psychological Society.

Within the College, as a Faculty we have contributed to the Assisted Dying group, highlighting some of the particular challenges and concerns of our patient group given their vulnerabilities. We have also inputted into the formulation working group set up in the College to ensure formulation skills are not lost in our specialty to maintain a holistic approach to patient care.

### Trainees

Last year in the autumn we hosted our first ID higher trainee welcome event online. We also had our online welcome event for ID run-through





trainees. These events are good platforms to connect with trainees, demystifies the ID Faculty for them and also give them insights about opportunities available in the ID faculty right at the outset. I had the privilege to present and attend the National ID ST conference in Liverpool hosted by higher trainees in November last year. Dr Jai Kumar and his colleagues had put together a stimulating programme. It was a delight to be amongst vibrant and enthused upcoming generation of consultants; the future of our specialty is in good hands.

I also wanted to take this opportunity to thank Abigail Swift, the higher trainee representative at the Faculty who will be finishing her term with us. We will be advertising this post in the next few weeks and I would encourage trainees to consider applying for this role. If this sparks your interest and would like to discuss this role, please get in touch with me.

A plea to my consultant colleagues to put yourself forward for the upcoming ST4 national recruitment for the August 2025 rotation. Participating in this process will ensure we continue to maintain the high-quality of candidates we select for higher training in our specialty. If you need more information regarding this process please contact the DME in your organisation or email [england.psychiatryrecruitment.nw@nhs.net](mailto:england.psychiatryrecruitment.nw@nhs.net)

### Book publication

I wanted to bring to your attention the Frith Prescribing Guidelines, 4th edition published by the Cambridge University Press has just been released. The guidelines are conceived and led by eminent expert clinicians working in the Learning Disability services. I am sure the book will be very handy to clinicians in day-to-day clinical practice.

### Spring conference, 25 April

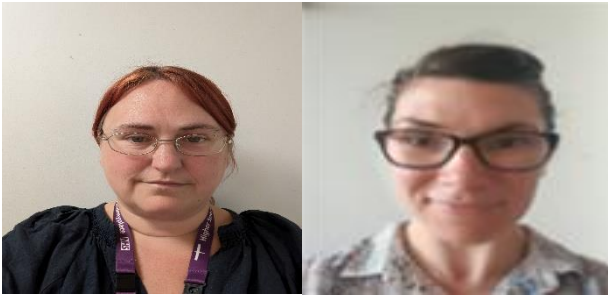
Please pencil in date for the diary for the upcoming Spring conference: 25th April 2025, at RCPsych, London.

I would like to say a huge thank you to you all for your support and commitment and the work you do.

Sending you all warm wishes in this cold weather. Keep safe and warm. Once again here's wishing and hoping you and your families have a fantastic 2025!

**Inder Sawhney**  
ID Faculty Chair

## Higher Trainee Rep Update



Merry Christmas and a Happy New Year to you all!

In the last 6 months, the higher trainee reps have been busy with various projects in the ID Faculty. The biggest has been the launch of the first 'Welcome Event' in October, which many of you may have attended. David (previous higher trainee rep) was instrumental in helping to pull this together. We had several talks from members of the ID Faculty, from Dr Inder Sawhney, who gave an overview and current priorities of the ID Faculty, to Dr Lindsay Mizen, who spoke about academic opportunities in ID Psychiatry.

We discussed the numerous opportunities for ID trainees to get involved with the faculty from helping with the Online Accessible Intellectual Disability Mental Health Information led by Dr David Anderson to the faculty newsletter led by Dr Mustapha and Dr Rudra.

The completed feedback forms from this event were all positive and recommended that others attend. The hope is to hold this 'Welcome Event' biannually or annually, which is targeted at new ST4s but may be helpful for anyone wanting to understand the ID Faculty more. A big thank you to everyone who attended or presented.

In other news, updated dementia in ID guidelines will be launched this year, a joint project with the British Psychological Society. Work continues on the update for the Challenging Behaviour in ID guidelines, again jointly with the British Psychological Society.

Liz and I continue to share trainees' views in the ID Faculty executive committee meetings, which

are held three times a year. We also attend various other working groups, like the National Recruitment group.

We'll be arranging a regional rep meeting in January/February time. Look out for this!

Lastly, my time as a national higher trainee representative is coming to an end. I've been doing this role on and off for the last two years, with a break for maternity leave in the middle. It has been a pleasure to listen to the successes and challenges of ID trainees across the four nations during this time. I've enjoyed sharing these experiences with the wider ID Faculty and advocating for projects like the 'Welcome Event' to improve the ID trainee experience.

As always, there is more work to be done, and I'm aware of the desire for a Welcome page for ID ST4s on the Royal College of Psychiatry website that we have yet to start.

Kitti will advertise the national higher trainee representative roles in February and March. If anyone is interested but would like to discuss applying first, please get in touch.

National Higher Trainee ID Representative role-contact **[Abigail.swift@wales.nhs.uk](mailto:Abigail.swift@wales.nhs.uk)**

Accessible website / easy read information for those with ID – contact

**[David.anderson@cntw.nhs.uk](mailto:David.anderson@cntw.nhs.uk)**

Ongoing editorial work on the newsletter – contact **[newsletter.psychid@gmail.com](mailto:newsletter.psychid@gmail.com)**

## Author Details

**Dr Elizabeth Anslow and Dr Abigail Swift**  
Faculty of ID Higher Trainee Reps



## An interview with...

### Dr. Ken Courtenay

#### NHS England Learning Disability and Autism Programme National Director

By Dr Maruf Mustapha



#### Tell us about yourself, your history and the journey to becoming an ID psychiatrist?

I'm Dr. Ken Courtenay. I grew up in Dublin, where my family lives, and went to university there. When I left university, I was interested in two specialities: general practice (GP) and psychiatry. I moved to London and completed GP training in 1992. Then, I went to New Zealand for a year and worked in psychiatry. On my return, I entered the psychiatry training programme at St. George's Hospital in London.

I fell into working with people with intellectual disabilities. I was offered a six-month job as a core trainee. This was a fascinating and stimulating experience with a really inspirational consultant. Having done general practice, I had a strong orientation towards people's physical health so the fact that this population had big issues with their physical health appealed to me as a clinician.

Along the way, I've earned two master's degrees and various other certificates. I continue to be a member of the Royal College of General Practice.

#### What are your main roles currently?

I am a consultant psychiatrist in a low-secure forensic service in North London. I have been doing this since March 2020. My second role is currently as a national director with NHS England in the Learning Disability and Autism programme which I have been doing since January 2024. So, my week is split between two days of clinical work and three days of work with NHS England.

#### What one piece of advice would you give to someone who wants to take up similar responsibilities?

First, I'd say not to rush or expect too much but to keep grounded in your clinical work over the years. It was never my intention to become a national clinical director or to hold other previous roles, such as being past chair of the ID Faculty. They just evolved as things developed for me in my career.

When I started as a consultant, I was interested in clinical services and getting embedded in them. This requires working with clinical and managerial colleagues in the trust and other services and, crucially, working with Commissioners. So, the role was more than just delivering clinical care, which is especially important in intellectual disabilities where you must connect with other people in the system to get the best for the patients you're working with. Interestingly, looking back, I think that's what set me up for taking on non-clinical roles. It really helped me because I can see from different perspectives how things function in the work I now do with NHS England.

#### What are your aims and ambitions as the National Clinical Director of the Learning Disability and Autism Programme in NHS England?

Well, there are a few things I want to achieve. The programme's key improvement objectives include inpatient services, community teams, and autism diagnosis.

We have done well with inpatient services, given that we have gone from 2500 patients to 1800. It's taken a long time but it was never going to be achieved overnight, so we've done well in that sense. We are now focusing more on improving community services. I think many community services have adapted well, but others have found it difficult, and we need to support services in adapting and innovating.



Another area I'm keen on improving is children's learning disability services and offender services. Children's services because they are universally not the same around the country, and I've always been a firm believer that if we get it right for children, we can make a big difference for families and the adults. Working in adult services, I learned that if things had only happened in childhood, we would not be dealing with challenging behaviours to the same degree as we often do.

The other area that I feel is very important is research on intellectual disabilities. I think we can lead on this by considering the priorities in terms of research and what funding NHS England could provide.

**In your role as a CQC advisor, can you share some of your experience on very good ways of working that you've observed?**

I have seen models of good practice in inpatient services delivered by some companies in the independent sector. They had single-occupancy inpatient services for people where the person had their own facilities. I liked that model, particularly when dealing with people who might find it difficult to tolerate others constantly around them due to their hypersensitivities and needs. It also allowed the staff to get to know people more individually and what they like. I think that model needs to be replicated not just for inpatient services but also for supported living.

**Are there any current innovations you want to see implemented here?**

Yes -Emotional Development. Anton Došen from the Netherlands developed the concept of Emotional Development that is very popular among the Dutch, Belgians, and Germans. Tanja Sappok came to the College for a one-day meeting about this. It has not caught on in the UK or Ireland, and I think we need to revisit it.

**You are a well-published and cited medical educator. Do you have a personal favourite among your many publications?**

I'm proud of the College Report [CR230](#) on ADHD and intellectual disabilities, led by Bhathika Perera and published while I was Chair of the ID Faculty. It was a pivotal publication in our understanding of ADHD-ID and has shone a light on the concept of ADHD in people with ID.

**You have also edited one of the journals of intellectual disability. Do you have any pro tips for potential writers reading this newsletter?**

It can be very daunting to publish a paper in a peer-reviewed journal, but it is not the only way to be published. You can get things out there by taking small steps that will give you confidence. The important thing is to write and share it with other people for comment.

**Quick-fire questions:**

**Movie recommendations?**

Cabaret by Liza Minnelli and Michael York

**Most memorable holiday?**

It was the first time I went to New Zealand.

**Favourite book**

The Magician by Colm Tóibín

**Thanks very much for sharing your time. There is so much more we could talk about. We look forward to you joining us again.**

**Author Details**

**Dr Maruf Mustapha**

ST6 in ID Psychiatry, Newsletter Lead Co-Editor

For the full interview please contact:  
[Maruf.Mustapha@lscft.nhs.uk](mailto:Maruf.Mustapha@lscft.nhs.uk)



## Alec Shapiro Presentation Prize Winner 2024

# Unravelling Safety Issues in Learning Disability Mental Health Care: Insights from Incident Investigations

By Dr. Nusra Khodabux

Patient safety is a critical concern in healthcare, particularly for individuals with learning disabilities receiving mental health care (1,2). To better understand the risks and improve quality of care, I conducted an in-depth qualitative analysis of serious incident investigation reports from a large NHS mental health trust.



The study examined 30 anonymized reports spanning 2014-2023, employing both content analysis based on the Yorkshire Contributory Factors Framework (3) (figure 1) and reflexive thematic analysis (4). This approach revealed recurring themes in factors contributing to incidents both at the sharp and blunt end of care.

## Key findings (Table 1):

**Situational factors:** The most prevalent contributors, identified 187 times across 28 incidents (31%), included complex patient behaviours and gaps in staff knowledge about learning disabilities.

**Active failures:** Issues such as non-adherence to procedures, diagnostic overshadowing, and communication breakdowns were observed 109 times across 29 incidents (18%).

**Organizational factors:** Resource constraints, unclear policies, and infrastructure limitations were identified 107 times across 27 incidents (18%), suggesting systemic challenges.

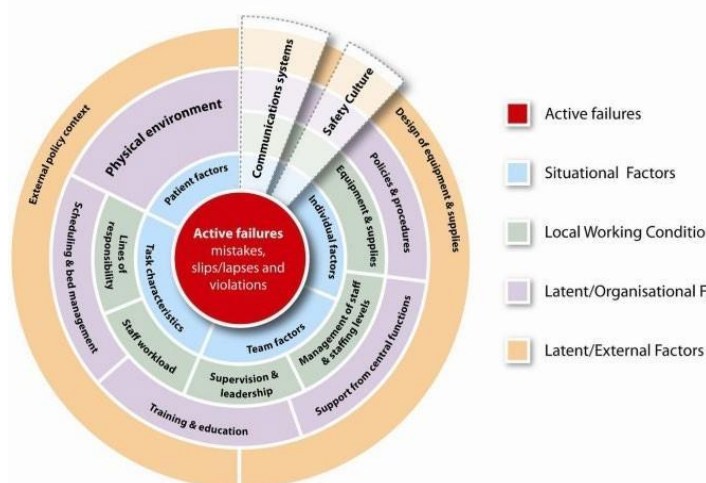
**Communication systems:** Weak communication between staff-staff and staff-carers was noted 75 times across incidents (12%), highlighting significant information flow problems.

**Local working conditions:** Poor skills mix, staffing levels, and unsuitable infrastructure were identified 62 times (10%), indicating immediate workplace challenges.

**Safety culture:** Reluctance to voice concerns and normalization of protocol deviations appeared 51 times across 22 incidents (8%), suggesting ingrained cultural issues.

**External pressures:** Factors beyond the trust's direct control, such as breakdown of community support, were identified 15 times across 15 incidents (2%).

The study highlights the complex interplay between patients' needs, staff capabilities, organizational systems, and broader societal factors in shaping safety outcomes. It emphasizes the importance of comprehensive, system-wide approaches to improving care for this vulnerable population.



**Figure 1 – Yorkshire Contributory Factors Framework**



Contributory factors based on the Yorkshire Contributory Factors Framework (Total N=606)	Number of serious incidents (n, %)	Number of instances across all incidents (n, %)
Situational failures	28, 93%	187, 31%
Active failures	29, 97%	109, 18%
Organisational factors	27, 90%	107, 18%
Communication systems	23, 77%	75, 12%
Local working conditions	22, 73%	62, 10%
Safety Culture	22, 73%	51, 8%
External factors	15, 50%	15, 2%

**Table 1 – Contributory Factors Analysis**

### Recommendations include:

- Enhancing staff training on learning disabilities, with a focus on practical, applied knowledge.
- Improving communication systems to ensure crucial information transfer within and across organisations.
- Addressing cultural barriers to speaking up about concerns.
- Strengthening community support structures to prevent unnecessary hospitalizations.

### Addressing the Challenges:

Our Trust already has proactive strategies to address many of these issues. Initiatives include allocating funding for leadership roles, implementing robust workforce plans, improving digital communication systems, promoting the Freedom to Speak Up Guardian, and implementing the Learning Disabilities and Autism Collaborative. The new national patient safety strategy, including the Patient Safety Incident Response Framework (5), also holds promise for more comprehensive investigations and systemic improvements.

This research demonstrates the value of aggregated analysis of incident data to identify patterns and priorities for improvement. It also

highlights the need for high-quality investigations that explore deeper systemic and cultural factors contributing to safety risks.

As we strive to enhance care for individuals with learning disabilities, insights from studies like this can guide targeted interventions and policy changes. By addressing the multi-faceted challenges identified, we can work towards creating safer, more responsive mental health services for this important patient group.

I welcome further discussion on this important subject. If you have insights or experiences to share regarding safety in learning disability care, please contact me at [Nusra.khodabux@nhs.net](mailto:Nusra.khodabux@nhs.net).

### References:

- (1) Heslop P, Hoghton M. The learning disabilities mortality review (LeDeR) programme. British Journal of General Practice 2018;68(suppl 1).
- (2) Taylor JL. Transforming care for people with intellectual disabilities and autism in England. The Lancet Psychiatry 2021;8(11):942–944.
- (3) Lawton R, McEachan RR, Giles SJ, Sirriyeh R, Watt IS, Wright J. Development of an evidence-based framework of factors contributing to patient safety incidents in hospital settings: a systematic review. BMJ quality & safety 2012;21(5):369–380.
- (4) Braun V, Clarke V, Hayfield N. Thematic analysis: A reflexive approach. : SAGE Publications; 2023.
- (5) England N, Improvement N. Patient safety incident response framework 2020. London, NHS England and NHS Improvement 2020.

### Author details

#### Dr. Nusra Khodabux

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## Gregory O'Brien Travelling Fellowship Award

### The Gregory O'Brien Travelling Fellowship

By Dr Louise Howitt

Greg O'Brien was 59 when he died in 2018. He was a key developer of the specialty of Intellectual Disability (ID) psychiatry, first in the UK and in Australia. This is an excerpt from an article written about him shortly after his death:



*"Greg entered ID psychiatry in the 1980s at a time when its role and future were being questioned. Over the next 30 years, he helped develop its clinical and academic character... An unfashionable specialty, Greg made sure the Faculty of Psychiatry of ID would be a significant source of support for many isolated members"* (BJPsych bulletin)

The Gregory O'Brien Travelling Fellowship, awarded every two years by the RCPsych ID Faculty, aims to support and inspire trainees and early-career consultants in advancing their expertise in ID psychiatry (RCPsych website). It is awarded every two years, with the next submission date in December 2025. Details of the application process can be found on the website: [Intellectual disability faculty prizes and bursaries](#)



Photo: Gregory O'Brien

My interest in ID psychiatry began at medical school when I completed a dissertation focusing on co-ordinated care for children with Down Syndrome. After my foundation year, I took a break from medicine to work in the arts, leading dance workshops with various communities, including individuals with ID and autism. In 2021, I joined the Board of DanceSyndrome, an inclusive dance charity near Manchester, and I continue to run dance sessions for SEN students in Brentwood and adults with ID in London alongside my clinical work. As a core trainee, I was eager to pursue opportunities in ID psychiatry—a field I felt was sometimes overlooked in training—and was excited to discover this Fellowship on the ID Faculty website.

In December 2023 I wrote a proposal for an experience with CANDDID (the centre for autism, neurodevelopment disorders and intellectual disability), which is part of Cheshire and Wirral Partnership NHS Foundation Trust, set up in 2018 as a centre of excellence for ID psychiatry. In my exploration of centres of excellence, CANDDID stood out to me because of its distinctive blend of rigorous research and academic emphasis, coupled with inclusive clinical practices and a commitment to educating professionals and caregivers. My proposal listed a number of academic and clinical aims and how I intended to accomplish these during my time with the team.

When I was awarded the Fellowship, I arranged to travel to Bramhall and work with the CANDDID team over two weeks in July 2024. Prof Sujeet Jaydeokar and Prof Mahesh Odiyoor kindly put together a very interesting and varied timetable for me, which included:

#### Clinical

- Shadowing MDT including physiotherapy and SALT home visits
- Attending inpatient ward rounds, ward reviews and assisting on ward tasks
- Sitting in on specialty doctor/ consultant clinics
- Attending referral meetings

## Academic

- Attending University of Chester Masters teaching for neurodevelopmental disorders

## Research

- Developing a research proposal with the professors from CANDDID

This experience was an invaluable opportunity for me, deepening my understanding of a psychiatrist's role within an ID psychiatry team. In particular, it highlighted the critical importance of the multidisciplinary team (MDT) approach in ID care. While I had previously observed this approach in my work, this experience allowed me to appreciate the psychiatrist's unique perspective and contributions to holistic ID care. Working alongside the dedicated team at CANDDID was inspiring, motivating me to refresh my Makaton skills and to encourage colleagues to engage with Makaton as well.

I was particularly excited to have the opportunity to collaborate with professors on a research proposal exploring dance and movement within the ID population. During a meeting with Prof. Jaydeokar to discuss my academic goals for the Fellowship, he inquired about specific areas of interest I wished to research. I shared my background in the arts and my experience working with adults and children with ID, using dance, movement, and creative arts as therapeutic tools. Our discussion highlighted that while the arts are often employed in both inpatient and outpatient settings for the ID population, there is a lack of robust evidence to support the provision of these activities within the NHS. To address this gap, I expressed my interest in investigating the existing evidence in this field. Together, Prof. Jaydeokar and I developed a proposal for a scoping review titled: *"What is the current evidence for the use and outcomes of dance and movement interventions in mental health services for people with intellectual disability?"* I am currently in the data-gathering phase of this project. Collaborating

with colleagues who are passionate about driving positive change through rigorous research and academic work in ID psychiatry has been very inspiring.

Ultimately, this Fellowship has reinforced my commitment to pursuing a career in ID psychiatry, with a personal goal to contribute to meaningful advancements in the field both in the UK and internationally.

In addition, I am grateful for the valuable professional connections I have made in the dynamic field of ID psychiatry and look forward to fostering these relationships in the future.

## Thank you to:

- RCPsych ID Faculty
- Kitti Kottasz
- EPUT, especially Dr Pathak, Dr Ali and Dr Gaunekar
- Henrietta De Gale at CANDDID
- Prof Sujeet Jaydeokar and Prof Mahesh Odiyoor
- All the staff at CANDDID

## Links to References:

[Gregory O'Brien: MB ChB MA MD FRCPsych FRCPC FRANZCP | BJPsych Bulletin | Cambridge Core](#)

[Intellectual disability faculty prizes and bursaries](#)

[CANDDID: Cheshire and Wirral Partnership NHS Foundation Trust](#)

## Author details

**Dr Louise Howitt**  
CT2 Psychiatry  
South EPUT



## Psych Star

### Psychiatry has been a highlight of my medical school experience.

By Megan Grainger

With every psychiatrist I have met, every talk and lecture I have attended, and every topic I have studied, nothing has grabbed my attention more than psychiatry. So, when the opportunity presented itself to meet MORE psychiatrists, attend MORE talks and conferences, and gain MORE experience, it was a no-brainer that I had to apply to the Psych Star Scheme. I applied and was accepted into the scheme, specifically as an Intellectual Disability Psych Star, and I am grateful to have been able to explore this area of Psychiatry through the scheme.



The first and most important aspect of this scheme is the mentoring. Without my mentor, Dr Singh, I would not have received any of the opportunities I have had. He was so understanding of what I wanted and took the time to introduce me to other psychiatrists in my area, point out books he felt were important to read, and suggest other beneficial experiences.

For example, my mentor suggested a course in Makaton, and, as someone who has already learnt British Sign Language (BSL) in a phase of lockdown boredom, and has a 942 day streak on Duo Lingo learning Spanish (but don't try to talk to me in Spanish I'm still not confident!), this was something I immediately wanted to do. Therefore, I achieved my level 1 and 2 qualifications in Makaton, which will significantly help me in my career as a doctor, where I will come across new people every day who communicate in such different ways.

Following on from my talks with my mentor, I attended the Intellectual Disability Conference in Leeds, which was the first non-university ran conference I have attended. This was a phenomenal experience, despite the storm leaving me stranded in Leeds for an additional night! The talks were incredibly interesting, and despite there being few students, I did not feel as if I was an imposter, or too young to be there. Everyone I spoke to made me feel included and as though I was an equal.

One specific talk stood out to me. This talk discussed how there is an increased likelihood of those with autism spectrum disorder (ASD) experiencing gender dysphoria, whilst also having an increased difficulty in handling these emotions. Following this talk, I read more about the topic as it was something I was not aware of prior. Whilst more research is needed, a systematic review<sup>1</sup> found a higher prevalence of gender dysphoria amongst people with autism. From this I am considering doing a project this year surrounding the usage of puberty blockers in children, as part of my intercalated BSc year.

It is truly difficult as an early-year medical student to get experience in any area of psychiatry except for a few lectures on the basics of depression. This is something that worries me because, as much as I love the field of psychiatry, before this scheme I hadn't had any real hands-on experience. Dr Singh introduced me to his contacts in London, and I had a wonderful 2-week placement in community Intellectual Disability. I learnt so much over those 2 weeks, and I am pretty convinced that I want to go into community psychiatry. Talking to patients for upwards of half an hour, instead of the typical 10 minutes, was something I adored. I loved getting to know the stories of these people and their families, and I can truly see myself settling down into this specialty.

If it wasn't for the Psych Star programme, it would have taken me until 5th year of University to truly discover if Psychiatry is what I wanted to do. This is why I'm so thankful for all of the people who have taken me through this experience,





from the team who run the Psych Star scheme, to my mentor, and the Psychiatrist giving me the opportunity to shadow her.

Finally, I attended not one, but two, conferences in 2024. The first one was the Royal College of Psychiatrists International Congress in Edinburgh. Before this I hadn't been to Edinburgh, so this was not only an amazing experience to learn about the deeper levels of Psychiatry, but also a lovely time away exploring a new place and getting involved in Fringe Events. Then, I attended the 2024 annual Intellectual Disability conference to give a talk on my time as an Intellectual Disability Psych Star, which was one of the first times I have done public speaking on such a big scale! Whilst I was terrified to do this talk, so many people came to talk to me afterwards and tell me their stories and complimented my talk, it was definitely a huge step in the right direction for my future in public speaking.

Overall, being a Psych Star was an unforgettable experience, and I'm truly sad that it is over. While it has been stressful around exams and placement, I am grateful for the understanding of all of those involved to be able to still make the most out of it. I could not thank the Royal College of Psychiatrists more!

## References

1. Thrower E, Bretherton I, Pang KC, Zajac JD, Cheung AS. Prevalence of Autism Spectrum Disorder and Attention-Deficit Hyperactivity Disorder Amongst Individuals with Gender Dysphoria: A Systematic Review. *Journal of Autism and Developmental Disorders*. 2020; 50 (3): 695–706. 10.1007/s10803-019-04298-1.

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## QIP/Audit

# Quality Improvement Project to Reduce Did Not Attend Rates in Psychiatry Outpatient Appointments

By Dr Heena Mistry

## Introduction

An audit was completed to reduce Did Not Attend (DNA) rates in the East North East (ENE) Leeds Community Learning Disability Team using the guidance provided by NHS England as part of the long-term goals to reduce lengthy waiting lists and reduce costs.

## Background

ENE Community Learning Disability Team are a mental health team that consist of psychiatrists, psychologists, physiotherapists, dieticians, occupational therapists, speech and language therapists, learning disability nurses and support workers. We help to ensure that people with learning disabilities receive the same care and treatment as everyone else when there is a concern about their physical or mental health and work with other professionals to ensure the individual's health needs are met.

NHS England have provided guidance to support outpatient services to reduce DNA rates. Out of 103 million outpatients booked in 2021/22, 7.6% ended in 'DNA'; this equates to 650,000 monthly appointment slots<sup>1</sup>. Millions of pounds are lost every year as a result. NHS England emphasized the need of attempting to decrease DNAs as part of the NHS long-term goals to shorten lengthy waiting lists for patients to receive the necessary care, particularly in the wake of the COVID-19 pandemic. Reducing outpatient appointment DNAs to even 2%, according to estimates, the NHS could save £266 million<sup>1</sup>. Sending reminders (letters, text messages, telephone calls) has been shown to reduce DNAs by up to 80%<sup>1</sup>.



The reasons behind DNAs are complex, however if we can try and understand some of the reasons why they may occur, our services can try and make positive changes to reduce DNAs to ensure appointments are not being wasted and improve patient experience. Reasonable adjustments often need to be made for our patient group to ensure equal access to healthcare and therefore having a system that better allows patients and their carers to take control of their appointments could help reduce health inequalities. We wanted to complete this quality improvement project as a starting point to reducing DNAs in the ENE CLDT.

## Aims and Objectives

### Aims:

- To reduce did not attend (DNAs) in the East North East Community Learning Disability Team outpatient services

### Objectives:

- Quantify number of outpatient clinic DNAs from June 2023 - January 2024
- Understand the reasons for why DNAs occurred
- Explore and test ideas for reducing DNAs of psychiatry outpatient (medical) appointments
- Continue to monitor DNAs internally (as part of the second PDSA cycle) following implementation of ideas to support efforts to improve services and quantify DNAs rate between February 2024 – July 2024 to monitor the impact of the changes

## Exploring the problem: reasons behind DNAs

Initially CLDT psychiatrists and the administrative team had a discussion about potential reasons for DNAs, considering the evidence described in the NHS England: Reducing DNAs report. Suggested reasons included:

- Patient/carers unaware of appointment

- Patient was not brought to the appointment by a carer or guardian responsible for their care
- Patient unable to attend but has difficulties cancelling or rearranging their appointment
- Appointment booked far in advance and patient not being given a more recent reminder
- People with learning disabilities may struggle to attend appointments for a number of reasons and may require reasonable adjustments to support their attendance to appointments
- Limited clinic days/times making it challenging to find a suitable appointment
- Unclear, inaccessible or incorrect appointment information given to patient
- Parent/carers difficulty taking time off work (particularly with face to face appointments). CLDT may need to work around the availability of the patients' carer or consider a telephone/video consultation instead
- Cost issues e.g. transport costs
- Social stressors such as difficult home lives, complex backgrounds often lead to DNAs. They may need additional support to attend appointments.

We then analysed our own data around reasons for missed appointments. From June 2023 to January 2024, every DNA was documented. Where patients had provided a DNA explanation this was recorded (see appendix), however recording of why DNAs had occurred was not consistent across the team and for all patients. Of the explanations recorded patients not receiving appointment letters and/or forgetting about appointments were most common reasons given.

Following our exploration of the problem and why DNAs occur we decided to test the idea of sending an Easy Read appointment confirmation letter and issuing a telephone reminder 2-3 days before each appointment.



While it is acknowledged that there are many further factors that impact on DNAs, this intervention was thought to be most likely to achieve significant impact given the short time and resource available for the project.

### PDSA 1: Testing our improvement idea

From August 2023 onwards, we ensured that an easy read appointment letter was sent and telephone reminder 2-3 days before the appointment was given. This was the primary step toward decreasing DNA rates/times and ensuring patients attendance. A member of the administrative team made a telephone call to remind the patient/carer of the time and location of the appointment, including the name of the doctor they would be seeing. If there was no answer, a voicemail would be left explaining the same information. In our patient group, it is usually the carer who is reminded.

From February 2024 – July 2024, any further DNAs were documented and again, DNA explanations were recorded. Again, we noted inconsistencies in how DNA explanations were recorded on our system.

All patients had received a letter to confirm the appointment as this was checked on care director. Most patients/carers were contacted via telephone to remind them of the appointment.

### Results

In the preceding period, average DNA rates were 12.1%. This was reduced to 4.7% following the implementation of our improvement idea (appointment letters and telephone reminders). This represents a 7.4% decrease (see Figure 1). The low number of appointments, including other factors (bad weather, holidays) has led to the exclusion of the January results. This primary action shows that effective, accessible patient/carer communication is vital, including systems being in place internally to ensure that this process is conducted. Our results showed an improvement in DNA results if these actions are undertaken.

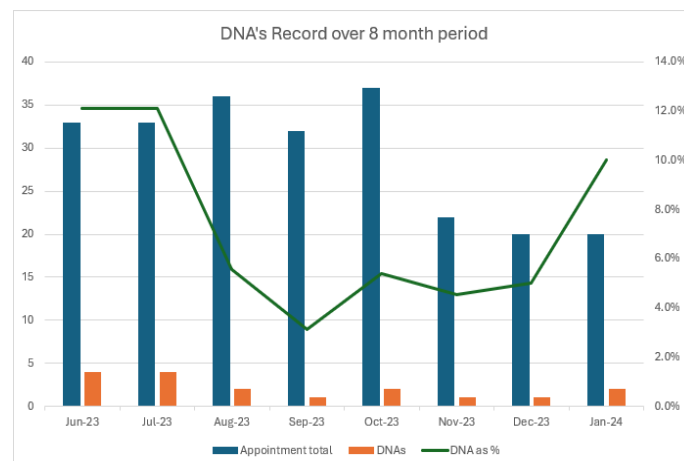


Figure 1: DNA rates from July 2023 – January 2024

Further DNAs were recorded from February 2024-July 2024 (see Figure 2). There were 161 medical psychiatry appointments in total. There were 7 DNAs in total, which is a DNA rate of 4.3%. The DNA rate remains low. Out of the 7 DNA's no reasons were recorded for 4 appointments as there was no answer when contact was made. Follow up appointments were subsequently re-arranged. The spike in DNAs that can be seen in March 2024 coincides with a period of leave taken by the admin staff who usually made telephone contact with the patient or carer a few days prior to the appointment. One patient phoned on the day to rearrange due to forgetting about the appointment and 1 carer cancelled due to difficulties with getting to clinic on the day.

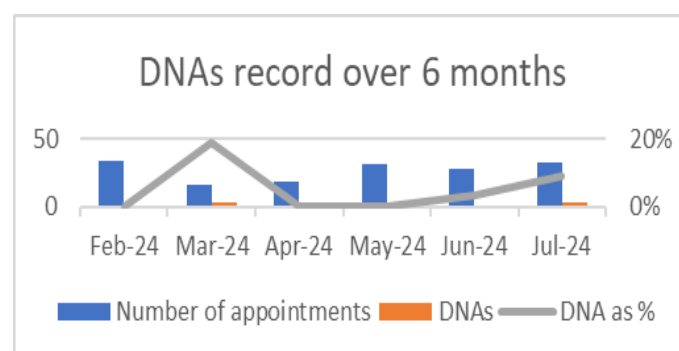


Figure 2: DNA rates February 2024 – July 2024

### Conclusions

This was a small study to explore and positively impact upon the problem of DNAs within a specific group of Learning Disability patients. We tested the simple interventions of sending out an Easy Read appointment letter and making a reminder call 2-3 days prior to the appointment

to assess whether these could help reduce rates of DNAs. Our results indicated that these interventions had a positive effect and we saw a reduction in DNAs when the measures were implemented.

While our results show the potential for significant positive impact of the interventions tested, our sample was small and could benefit from further exploration across the wider service and other Learning Disability teams.

Our work has highlighted the need for robust administrative systems that ensure a consistent service to patients during periods of staff leave and other unforeseen circumstances. Further work could explore the potential for these interventions to be fully adopted and embedded within the service's admin and appointment booking processes. Similarly, this project has identified work required to improve consistency when recording reasons for DNAs.

### Next Steps

As mentioned above, it is important that we assess the sustainability of the interventions we have tested in this project and explore opportunities to embed them as standard practice within our service's processes.

There is much opportunity to conduct further research into DNAs, learn from best practice elsewhere and explore further interventions beyond the scope of this initial project. This may include options for automated reminder systems such as text messages or digital patient portals that can give patient/carers more control over appointment bookings. These may be costlier in the short term but be less resource intensive over time.

It is important that we share our findings as widely as possible so that they may add to the body of evidence and insights into this important topic. We may seek opportunities to work collaboratively with other Learning Disability teams to increase our shared learning and knowledge in this area.

### References:

1. NHS England (2023) Reducing did not attends (DNAs) in outpatient services. Available at: <https://www.england.nhs.uk/long-read/reducing-did-not-attends-dnas-in-outpatient-services/> (accessed on 20/02/2024). NHS Improvement (2023)

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## QIP/Audit

# Audit of Healthcare Standards for the Learning Disability Population in South West Yorkshire NHS Foundation Trust: A Review Based on NICE Guidelines

By Dr Gabriel Michael and Dr Gareth John



## Introduction

The healthcare needs of individuals with Intellectual Disability (ID) are unique and require specific consideration to ensure equitable access to high quality care. The National Institute for Health and Care Excellence (NICE) provides evidence-based guidelines to support healthcare professionals in delivering high-quality care to this population (NICE, 2019). This article presents an audit of healthcare standards for individuals with ID in the UK, focusing on compliance with NICE guidelines.

## Background

Individuals with ID often face significant health inequalities, including disparities in access to healthcare services, diagnostic overshadowing, and inadequate provision of reasonable adjustments. Recognising these challenges, NICE has developed a series of guidelines to promote best practice in the care of individuals with ID. These guidelines cover various aspects of healthcare, including assessment, diagnosis, treatment, and support services. (NICE, 2015)

## Audit Methodology

The audit was conducted using a systematic approach, reviewing a specific ID clinic's adherence to NICE guidelines in the provision of care for individuals with learning disabilities. Key areas of focus included:

- Percentage of patients seen in ID clinics with a valid annual GP (General Practitioner) health check.
- The percentage of patients being asked about their own physical health by their treating psychiatry team.

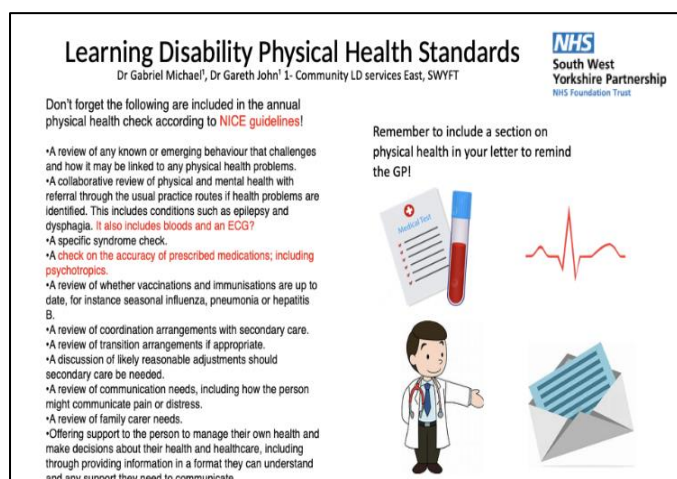
This review was performed via use of the online electronic system used within the trust as well as a review of the clinic letters (also stored within this electronic system; SystemOne).

## Findings

The initial audit demonstrated a need to ensure that our GP colleagues are completing annual health checks, as per the NICE guidelines (NICE 2015). 81% of the 43 patients seen in the month of April had their health check within the last year. 93% of the patients seen had been asked about their physical health at their review with the psychiatry team.

This prompted our team to implement posters (See Figure 1) across the clinic sites ensuring that physical health concerns are being addressed by reviewing clinicians. Our letter formats were amended to ensure that this took place. A re-audit demonstrated an improvement in the percentage of service users being asked about their physical health.





**Figure 1: Poster displayed across clinic sites**

In the month of May, 100% of the psychiatry reviews consisted of a physical health check. However, 76% of the 30 patients seen that month had been reviewed by their GP in the past year. This is a local target that requires improvement.

This audit incidentally highlighted the high rates of non-attendance in clinics which is a local, as well as national issue (Table 1). Addressing these challenges requires a multi-faceted approach, including enhanced training for healthcare professionals, standardised provision of reasonable adjustments, improved coordination of care, and robust monitoring and evaluation mechanisms.

Month (2024)	Total Number of patients scheduled to be seen	Total Number of patients seen	% patients that did not attend clinic	% of patients with valid annual health check	% of patients with physical health review at LD clinic as per letters
March	35	26	25.7	92.3	88.5
April	60	48	20	81.3	93.75
May	36	30	16.6	76.7	100

**Table 1: Table of results**

## Conclusion

The audit highlights both the ability to improve practice with minor intervention and areas for

improvement in the provision of healthcare services for individuals with ID in our service. The audit also highlights the importance of adhering to the recommended NICE guidelines. By focusing on the needs of individuals with ID and aligning healthcare practices with NICE guidelines (NICE 2015 & NICE 2019), we move closer to ensuring equitable healthcare outcomes for everyone.

## References

Overview: Learning Disability: Care and support of people growing older: Quality Standards (2019) NICE. Available at : <https://www.nice.org.uk/guidance/qs187>

Quality statement 2: Annual health check: Learning disability: Behaviour that challenges: Quality standards (2015) NICE. Available at: <https://www.nice.org.uk/guidance/qs101/chapter/>

Quality-statement-2-Annual-health-check (Accessed: 15 May 2024).

Wikipedia. (2020). SystemOne. [online] Available at: <https://en.wikipedia.org/wiki/SystemOne>.

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## Conference Watch

# Insights and Inspiration: Our Experience at the Faculty of Psychiatry of Intellectual Disability Conference

By Dr Megan Viegas and Dr Hannah Newman



## Day One - 3rd October 2024, Dr. Megan Viegas

As part of my Core Training in Intellectual Disability (ID), I was encouraged to get involved in the broader specialty, and attending the Faculty of Psychiatry of Intellectual Disability Conference on 3rd October 2024 was a key moment in my training. The event significantly deepened my understanding of this complex field.

The conference opened with a warm welcome from Professor Rohit Shankar, Vice Chair of the Faculty, setting the stage for an engaging agenda. The attendees included a diverse group, ranging from medical students to senior academics, alongside clinicians from various specialties, creating a collaborative learning environment.

### Featured Talks

Dr. Ken Courtenay, National Clinical Director for the NHSE Learning Disability and Autism Programme, discussed the challenges of providing equitable care for individuals with ID. His presentation highlighted ongoing barriers faced by clinicians in delivering consistent care.

Dr. Rachel Ruddy, Clinical Lead for Mental Health at the Government of Jersey, shared a thought-provoking talk on euthanasia and assisted

suicide for individuals with ID. The unsettling data from other countries raised ethical questions about our practices, inspiring my recent Journal Club presentation.

We also heard from Dr. Pamela Bowman, Academic Clinical Lecturer in Clinical Genetics, who introduced exciting advancements in early treatment for iDEND syndrome, a promising area of genetic research in ID.

### Networking and Shared Learning

During the break, delegates participated in poster sessions, exchanging ideas and making new connections. The collaborative atmosphere fostered rich opportunities for learning and professional growth.

### Supporting the Individual

Before lunch, three speakers emphasized patient-centered care. Dr. Mrityunjai Kumar, Specialist Registrar in All Age Intellectual Disability Services, reminded us that the true measure of success lies in the well-being of our patients, not just data collection when evaluating outcomes. Professor Regi Alexander, Consultant Psychiatrist and Clinical Lead in Forensic LD, discussed the risk of missing psychosis in patients with Autism, highlighting the complexity of such cases. Dr. Sam Tromans, Associate Professor at Leicestershire Partnership NHS Trust, presented his research on medical cannabis (CBD) for treatment-resistant seizures in individuals with ID.

### Therapeutic Interventions and Advocacy

The afternoon sessions focused on therapeutic interventions. Professor Heather Angus-Leppan, Consultant Neurologist and Epilepsy Lead, emphasized the importance of advocating for patients to ensure they receive the most effective treatments, especially amidst concerns about Sodium Valproate.

Professor Rob Howard, Professor of Old Age Psychiatry at UCL, explored new anti-amyloid treatments for Alzheimer's disease, urging



caution in interpreting emerging data. Professor Satheesh Gangadharan, Consultant Psychiatrist, discussed managing polypharmacy in older populations with ID, advocating a holistic approach to care.

### Addressing Current Challenges

The final sessions addressed several pressing challenges within the field. Professor Ian Maidment highlighted the concerning statistic that over half of individuals with ID are obese, calling for a more nuanced approach to managing this issue. Dr. Amy Blake, Consultant in CAMHS-ID, warned about the long-term consequences of closing CAMHS ID inpatient services, highlighting the shortsightedness of such decisions. Lastly, Dr. Lance Watkins, Consultant Psychiatrist, examined the social environment's impact on both patients and prescribing practices, reinforcing the need for a holistic treatment approach.

## Day Two - 4th October 2024, Dr. Hannah Newman

### Faculty Prize Presentations

I was fortunate to present my research as a faculty prize winner. The second day of the conference began with presentations from Dr. Ezhil Anand, the Academic Secretary, followed by Dr. Louise Howitt, winner of the Gregory O'Brien Travel Fellowship, myself (recipient of the Brian Oliver Prize), and Megs Grainger, winner of the 'Psych Star' award for medical students.

Four core and higher specialty trainees then competed for the Alec Shapiro Prize. Dr. Sarah Badger presented her study on the relationship between clinical presentation and care for adults with ID and epilepsy. Dr. Aurielle Goddard discussed her research on the prevalence and outcomes of childhood trauma in people with ID. Dr. Nusra Khodabux shared her findings on factors contributing to serious incidents involving adults with ID in mental health trusts. Dr. Oluwafemi Taiwo concluded with his

systematic review on mood stabilizers for individuals with Autism Spectrum Disorder.

### Terrorism and Trauma in Neurodevelopmental Disorders

Dr. Richard Taylor, Consultant Forensic Psychiatrist, and Fayz Allyboccus, National Service Lead from the Counter Terrorism Consultancy Service, spoke on counterterrorism in ID psychiatry. They shared case studies that highlighted the challenges of this work. Dr. Peter Beardsworth, Consultant Clinical Psychologist in Leicester, then gave a thought-provoking talk on trauma-informed care for people with ID, using a memorable case to illustrate its impact.

### Workshops: Standards and Stools

Delegates split into workshops, which were repeated to ensure everyone had the opportunity to attend both sessions. The Quality Network for Learning Disability Services team discussed their work with community ID services and the peer review process to promote high-quality care.

Dr. Richard Laugharne, Emeritus Consultant Psychiatrist, and Ruth Bishop, Occupational Therapist, from Cornwall Foundation Trust, led a session titled "Constipation: Unblocking the Problem," focusing on resources for managing constipation in people with ID and fostering a collaborative discussion.

### Research and Reflections

In the afternoon, Dr. Afia Ali, Clinical Reader in ID Psychiatry, presented a systematic review on behavioural and cognitive-behavioural interventions for aggressive behaviour in people with ID.

Professor Ashok Roy, OBE, reflected on the life of Jose Jancar and his own career, detailing societal, scientific, and healthcare advancements for people with ID. Dr. Harm Boer, Consultant Psychiatrist, responded to this insightful reflection.





Professor Raja Mukherjee, MBE, kept the learning going with a presentation on his work producing the report on FASD for the Royal College, offering new understandings of the syndrome.

To conclude the two-day conference, Professor Rohit Shankar awarded the Alec Shapiro Prize to Dr. Nusra Khodabux and the Poster Prize to Dr. Aurielle Goddard. We left inspired with new insights and renewed enthusiasm.

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## Medical Student Reflection

# Calm or Chemical Restraint? - The Fine Line of Psychotropic Medications for Challenging Behaviours in Intellectual Disability

By Meghna Nair



My name is Meghna Nair. I am a fourth-year medical student at the University of Leeds and have a keen interest in working with individuals with intellectual disabilities within psychiatry. This article summarises my learning and reflections on the use of psychotropic medications for challenging behaviours in people with an intellectual disability (ID).

## Introduction

The management of challenging behaviours in individuals with ID requires a multifaceted approach, and psychotropic medications have become a key component of this care. These medications can help manage severe behaviours, such as aggression or self-harm, which, left untreated, could impact quality of life and safety for the individual and others. However, the use of psychotropic medications in ID is a controversial topic, with concerns over "chemical restraint" whereby these medications may be used to control behaviour, as a substitute for behavioural interventions, rather than treating an underlying psychiatric condition. The use of psychotropic medications in managing challenging behaviours in individuals with ID presents a complex balance of benefits and risks.

## Current Debates and Evidence

On the one hand, psychotropic medications can be effective in reducing severe behaviours which may otherwise lead to harm or institutionalisation. For many individuals with ID,



psychotropics can offer improved behavioural stability, enhancing their ability to engage in day-to-day activities, subsequently improving quality of life. Managing challenging behaviours can also reduce the burden on caregivers, potentially providing a more supportive care environment. However, psychotropic medications are associated with a range of adverse effects, such as weight gain, sedation, metabolic syndrome, and extrapyramidal symptoms, which can reduce quality of life and lead to long-term physical and mental health complications (2). Interestingly, psychotropics may sometimes worsen behavioural challenges, leading to cognitive dulling, emotional blunting, or an increase in problematic behaviours, which can negatively affect overall cognitive function. Other notable risks involving psychotropic medications include polypharmacy and potential harmful drug interactions, and dependency and withdrawal issues from long-term use.

### Challenges in Practice

The complexity of this topic is heightened by various practical challenges, outlined below. Communication barriers in individuals with ID make monitoring and assessing medication efficacy difficult. This is further complicated by the fact that challenging behaviour can be influenced by numerous factors, including environmental conditions, physical health, and personal circumstances. Physical health often involves coexisting physical and mental comorbidities, making it challenging to determine whether symptoms stem from the primary diagnosis, medication side effects, or other health conditions.

### Ethical considerations

Ethics plays a key role in this debate, particularly concerning autonomy and consent to treatment. The concept of "chemical restraint" raises significant concerns surrounding autonomy, particularly in individuals with ID. When psychotropic medications are used primarily to control behaviour rather than for therapeutic purposes, it can undermine a person's autonomy,

especially if they lack capacity to consent to or understand their treatment. This highlights the importance of involving families and caregivers in the decision-making process and prioritising non-pharmacological interventions where possible. This requires clear communication about the purpose of the medication, potential benefits, and risks, ensuring that choices align with the individual's best interests. The ethical dilemma in determining "best interest" in this context lies in deciding whether to prioritise immediate quality of life by using medication to manage challenging behaviours, or to weigh the potential long-term risks associated with psychotropic drug use.

### My Experience

I recently encountered a patient with autism and moderate ID presenting with self-harming behaviours including biting, suffocating herself with bedsheets, and refusing food and personal care. These behaviours likely stemmed from a history of neglect and abuse, which had heightened her emotional distress and left her distrustful of carers. While psychotropic medication was initially considered for managing acute behaviours, the primary approach was multidisciplinary and trauma-informed, emphasising a stable routine, compassionate caregiving, and offering daily choices to help her regain control. Regular reviews aimed at reducing medication, and over time, her self-care improved, and incidences of self-harm decreased. This case gave me firsthand insight into the complexities involved in balancing medication and therapeutic care. The case highlighted how essential it is to look beyond immediate behavioural control with medication and focus on creating a safe, supportive environment where the patient feels secure and has a sense of autonomy. I now appreciate the value of regular medication reviews, not just to monitor for side effects but as an opportunity to reassess and gradually reduce reliance on medications as coping mechanisms improve. This experience emphasised the fine balance required when incorporating



psychotropic medication into a holistic approach in individuals with ID.

## Conclusion

Informed decision-making and a multidisciplinary approach are essential in managing psychotropic medication use for individuals with ID. A collaborative framework that includes input from the patient (where possible), caregivers, and professionals ensures a holistic approach to treatment that respects autonomy and prioritises well-being. Future research could focus on long-term outcomes of psychotropic use in ID, identifying non-pharmacological interventions that reduce dependency on medication. Prioritising communication support, comprehensive health monitoring, and better community care will significantly enhance outcomes for individuals with ID, ultimately improving their quality of life and promoting ethical, patient-centred care.

## References:

Sheehan R, Hassiotis A, Walters K, Osborn D, Strydom A, Horsfall L. Mental illness, challenging behaviour, and psychotropic drug prescribing in people with intellectual disability: UK population based cohort study. *BMJ*. 2015 Sep 1;351:h4326. 2 - NHS England. NHS

England» Stopping over Medication of People with a Learning Disability and Autistic People (STOMP) and Supporting Treatment and

Appropriate Medication in Paediatrics (STAMP) [Internet]. [www.england.nhs.uk](http://www.england.nhs.uk). 2024

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## Medical Student Reflection

## The Importance of Communication Skills

By Aleena Nauman

As part of my 5-week psychiatry block, I spent several days at an assessment and treatment unit for adults with intellectual disability (ID). These are my reflections based on my experience of inpatient ID psychiatry.



The biggest takeaway from my time on placement is the psychiatrists' communication skills. They are truly something to aspire to. I realised almost immediately how important a good rapport was for the patient to open up to the doctor, and how this rapport was established on nuances that I was at that time unable to pick up on. Initially, I found it daunting to speak to the patients. However, as I witnessed more conversations, I realised that the communication skills that ID psychiatrists use are those that have already been introduced to us at medical school, distilled into their purest forms.

The foremost rule of good communication is to listen – listening to understand not just to respond. While this is true for communicating with all patients, we may not always be the best at it in other healthcare settings, due to time constraints. However, it is essential for communicating with patients with ID. Patients with ID may need our help to link different thoughts, feelings, and behaviours. We need to be fully switched on if we are to even attempt to understand the workings of another's mind. We also need to listen carefully to pick up on anything that patients are struggling to express, so that we can probe it further. This is especially pertinent because coexistence of autism spectrum disorder and other neurodevelopmental disorders is common.



Patient's may struggle with social communication skills in addition to their ID and, therefore, need extra support to express their views.

Being attentive to non-verbal cues is even more important in the ID psychiatry setting because some patients may have speech and language difficulties. For example, observing a non-verbal patient's facial expressions, and how they move around the room and interact with people reveals their mental state, and changes in this. Thinking about the setting for patient reviews is also important, as sitting down in a room chatting may not work for some patients and we need to adapt to meet their needs.

Encouraging and empathetic communication is key to motivating behavioural change in all patients. In ID psychiatry, this may need to be revisited more frequently. Within psychiatry we meet patients who have had very difficult upbringings and childhood experiences. We know that these experiences shape people throughout their life. The impact of the ID psychiatry multidisciplinary team's use of empathetic and encouraging communication is seen in the patients' good relationships with staff. For some patients, it can be the first time they feel they can build sound relationships with professionals. This allows the multidisciplinary team to role model positive behaviour, which in turn, allows patients to be more involved in their care and decision making, and plan constructive changes for their life going forwards.

Overall, these excellent communication skills allow truly getting to know the patient as a person. I was struck by how the staff knew everyone like they were family. Understanding this patient group, with their complex needs, is key for the professionals involved who can be responsible for making big decisions for them.

Seeing the life-changing effects of the communication skills of ID psychiatrists has made me wonder not only what could be achieved if they were employed as effectively in all healthcare settings but also about how much

good we could do for everyone around us if we used them in our everyday lives. I will take these lessons in communication into my future practice as well as trying to incorporate them into my daily life.

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## In the Media

### Love on the Spectrum – TV Series Review

By Dr Barbara Veras

*Love on the Spectrum* is a reality show that has captured the attention of viewers worldwide, offering a unique glimpse into the dating lives of individuals on the autism spectrum. While the show has been praised for raising awareness and promoting inclusivity, it has also sparked controversy, with some questioning its portrayal of autism and relationships. As the author of this article, I acknowledge these differing perspectives and want to clarify that the opinions expressed here are my own and do not reflect the views or stance of the Faculty of the Psychiatry of Intellectual Disability.



In the era of social media and influencers, it comes as no surprise that reality TV is at an all-time high. Since modern life means being bombarded with information from across the globe 24/7, ranging from live coverage of active war zones, to closely following every step of your acquaintances' routines, it only makes sense that people find themselves craving more and more a brief escape from it all, and find themselves turning to what many have dubbed the infamous "guilty pleasure" that is reality TV.

Thanks to the prolificacy of streaming services, there has never before been so many options of reality TV shows, and more specifically, reality dating shows. From pop cultural staples like *Love Island*, many a show has tried to slightly alter the formula in order to keep things fresh. From shows like, *Love Is Blind*, where contestants have to try and find a connection without ever laying eyes on each other, to, on the exact opposite realm, *Naked Attraction*, where participants must choose a partner based entirely on physical traits, it is easy to see why many would consider the reality dating show phenomenon as the

previously mentioned "guilty pleasure". But along came a show that proves that this does not have to be the case.

As all media, reality series grow to reflect societal trends and the ever-expanding diversification and need to embrace inclusivity. Shows like *The Ultimatum* perfectly encapsulate that, with the established franchise recently releasing *The Ultimatum Queer Love*, which explores LGBT+ relationships.

*Love on the Spectrum* goes beyond your average dating show, by being comprised entirely of individuals on the autism spectrum. *Love on the Spectrum* is an Emmy award-winning reality series produced by Netflix. The show, originally an Australian production which has now expanded to the US, offers a heartfelt and authentic look at the unique challenges and triumphs experienced by autistic individuals as they navigate the complexities of dating and relationships.

The series has been praised for its respectful and supportive portrayal of its participants, providing insight into their own individual experiences, dreams, and aspirations. It follows several individuals, 6 core participants in total (plus their dates), each with different types of clinical presentations, and varying levels of independence, as they go on dates, meet potential partners, and seek meaningful connections.

One interesting aspect of the show is that it features an autism expert coach, Jennifer Cook, who works alongside some of the participants to help them in their search for love. Jennifer was identified as being on the spectrum late in her life, and according to her it made "everything before in [her] life make sense". Now, Jennifer's goal is to help autistic people bridge the gap between, what she calls, "what's going on the inside" and "what is shown on the outside". Autism is a constellation of behaviours and challenges, with difficulties with social cues being one of the most relevant when it comes to dating. Throughout the show, we see Jennifer



working closely with the neurodivergent participants, using roleplay as a tool to help them prepare for their dates. A notable example is when she encourages Abbey, a 23-year-old participant, to not be restricted to only her interests during a conversation with a potential love interest, but to also ask questions and demonstrate interest in whatever topic the other person may want to talk about. While this may be obvious for neurotypical people, anyone who are themselves autistic or is in close contact with autistic people, will recognise it as a common experience.

The series does not only show dating between autistic people, but also depicts autistic individuals who are dating neurotypicals. Dani, a 26-year-old woman, who was diagnosed with autism as an adult, shares the difficulties that she has encountered while dating in and outside of the spectrum: "A lot of people on the autism spectrum think I'm too smart and too motivated, while neurotypicals think I'm too strange."

Another participant, Kaelynn, is 24 years old and was diagnosed with autism when she was 10 years of age. She also has a diagnosis of learning disability, dyslexia, dyscalculia and ADHD. Despite living independently, working, and enjoying spending time with friends and family, Kaelynn has had similar problems to Dani, finding dating really difficult. She describes her struggles with social interactions: "It's hard to know what to say and what to do at the right times". Kaelynn has had quite a few bad experiences with dating, and, in a poignant moment, shared one instance where her date, a neurotypical man, got up and left her the minute she disclosed her autism diagnosis. Unsurprisingly, she is now quite nervous about sharing her diagnosis on the first date. The series follows her dating journey as she continues to search for a partner who is loving and understanding of her autism.

Meanwhile, for some participants, the show marks their very first attempts at dating. Subodh's journey is one the most heartwarming storylines in the series. Starting as a 33-year-old

man who had never been on a date before, viewers follow him as he is able to form a significant emotional connection with Rachel and successfully asks her to his girlfriend. Spectators will undoubtedly be left teary eyed as his mother and sister emotionally talk about the importance of such a milestone in his life.

The show's authentic yet sensible approach to the topic proved to be the recipe for a hit. Boasting the accomplishment of making it to the third most watched show upon its release, the sheer number of fans of the series show how *Love on the Spectrum* has succeeded in not only providing compelling entertainment, but even more importantly, it has brought autism to the mainstream, and in doing so has taken strides to demystify the autism spectrum disorder itself.

*Love on the Spectrum* excels in balancing humour and light-heartedness with genuine emotional depth, and in doing so, highlights a very important message to its neurotypical viewers: how the desire for companionship and love is a universal one. As a core trainee in an intellectual disability service, watching this reality series has significantly impacted my own practice, as it has heightened my awareness of the importance of discussing and promoting healthy romantic relationships. This newfound perspective has encouraged me to incorporate more conversations and guidance around this topic into my daily interactions with patients, ensuring they have the support and understanding they need to form meaningful connections.

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## **PRIZE WINNERS**

### **Alec Shapiro oral presentation**

Nusra Khodabux

### **Alec Shapiro poster presentation**

Aurielle Goddard

### **Professor Joan Bicknell medical student essay prize**

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**Congratulations all prize winners!**

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## **UPCOMING FACULTY CONFERENCE**

[Faculty of the Psychiatry of Intellectual Disability Spring Conference, 25 April 2025, In-person RCPsych, London / Live-stream](#)

## **SUBMITTING ARTICLES**

This is the ID Faculty members' newsletter and we encourage submissions from clinicians, students, service users, carers and members of the wider multidisciplinary workforce. We will consider any article that may be of interest to our readers.

The Editor reserves the right to edit contributions as deemed necessary.

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