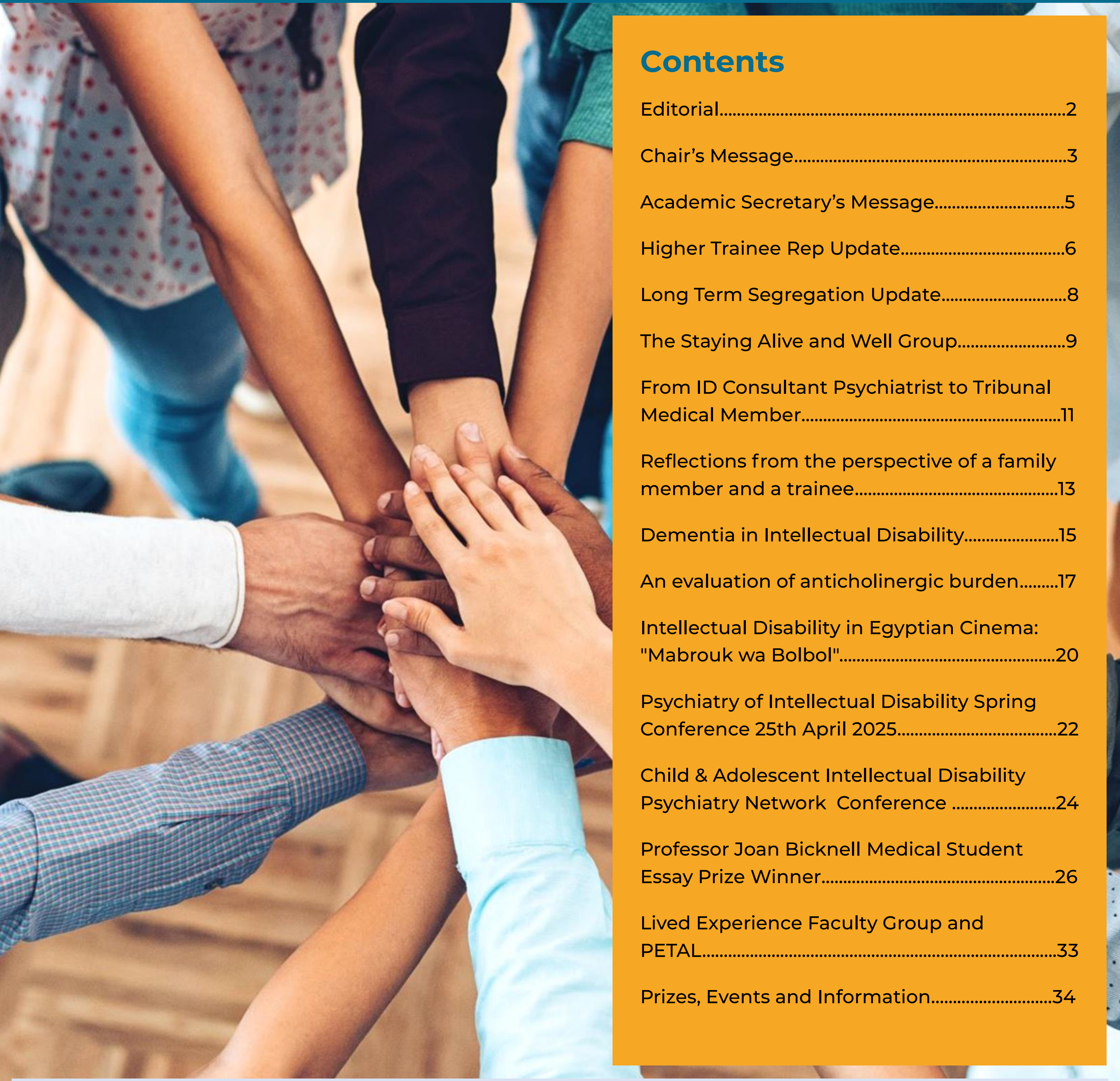
Faculty of Psychiatry of Intellectual Disability

Newsletter

July 2025



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Editorial

Sonya Rudra and Rachel Proctor

As summer approaches, we are delighted to welcome you to the July 2025 edition of the Intellectual Disability (ID) Psychiatry Faculty Newsletter.

This issue marks another step forward in efforts to highlight important developments, reflections, and innovations in the area of ID psychiatry. As always, we're grateful for the breadth of contributions from colleagues across the UK, and we're particularly pleased to see so many early-career voices adding to the conversation.

We begin with messages from our Faculty Chair, Dr Indermeet Sawhney, and our Academic Secretary, Dr Samuel Tromans. They discuss the launch of updated dementia guidelines, and share news on important initiatives, including the latest work from the National Medicines Safety Improvement Programme and the establishment of a support group for psychiatrists with lived experience of family/friends with ID. They also share details of the new Professor Sabyasachi Bhaumik Prize, to be awarded at our upcoming Autumn Conference in Leicester. In addition, we feature an update from our higher trainee representatives. Dr Abigail Swift reflects on her time in the role and hands over to new reps, Dr Ibrahim Younes and Dr Irshad Hussain. Irshad also co-authors an interesting audit on anticholinergic burden in ID inpatient settings, alongside Dr Rhyanna Morris, shedding light on the risks of polypharmacy and the importance of tailored prescribing.

We feature a faculty update on long-term segregation and seclusion, where Dr Anupama Iyer outlines the College's response to Baroness Hollins' report and invites your input on new terminology and safeguards. In our features section, we are privileged to share an interview with Richard Keagan-Bull from the Staying Alive and Well group, offering a vital reminder that people with lived experience must remain at the heart of all our work.

In the first of a new series on alternative roles for ID psychiatrists, Dr Elizabeth Carmody reflects on her transition from Consultant Psychiatrist to Tribunal Medical Member, highlighting the valuable and transferable skills ID clinicians bring to this role and the broader mental health system.

We hear from a range of medical students and trainees, whose contributions highlight emerging passions, practical challenges, and evolving understanding of ID psychiatry. Dr Raheen Fatima shares a deeply moving personal and professional reflection, while Ben Erin—winner of the Joan Bicknell Medical Student Essay Prize—writes powerfully about language, stigma, and patient-centred communication. Meanwhile, Je Ssy Low explores the complex challenge of diagnosing dementia in people with ID, and attempts to address some of the essential questions that remain at the heart of this clinical debate.

In our Media Watch, Dr Ibrahim Younes offers a cultural analysis of Mabrouk wa Bolbol, exploring how disability is portrayed in Egyptian cinema and the wider implications for stigma and social roles.

And finally, our Conference Watch includes a joint reflection by SAS doctor Dr Somya Pandey and medical student Meghna Nair on the Faculty of ID Spring Conference 2025, with each offering a distinct lens on the programme's highlights. Meanwhile, Dr Selin Aktan and Dr Ashley Liew report from the CAIDPN conference in Edinburgh, where the theme "Beyond Words" brought focus to the needs of young people with profound disabilities.

As editors, we are once again delighted by the quality and variety of submissions. Whether you're a seasoned Consultant, a motivated medical student, or somewhere in between, we hope this newsletter offers both practical insight and meaningful inspiration.

Thank you to our contributors, our editorial committee, and especially to Kitti Kottasz, whose behind-the-scenes support continues to be invaluable. We hope you enjoy reading this edition as much as we enjoyed curating it. And as always—if you're inspired to contribute to the next issue, we'd love to hear from you.

Sonya and Rachel
Lead Co-Editors

Chair's Message

Dr Inder Sawhney
Chair of ID Faculty

Dear Colleagues,

I hope this message finds you well and enjoying the beautiful weather.

It was wonderful to connect with many of you at the Faculty Spring Conference in London. A huge thanks to our Academic Secretary, Sam Tromans, and Ezhil Anand for curating such a fantastic programme. The day was full of insightful learning and genuine camaraderie. There was a vibrant energy as colleagues mingled, exchanged ideas, and shared laughter over coffee and lunch. I was especially delighted to meet several medical students and see their enthusiasm for our specialty. For those who joined us online—hopefully, this sparked a little FOMO (fear of missing out) and encourages you to attend in person next time!

Joint guidelines with BPS

I'm pleased to share that the guidelines on Dementia and People with Intellectual Disabilities have been jointly revised by the Royal College of Psychiatrists and the British Psychological Society (BPS). These updated guidelines are grounded in the latest evidence and are designed to support clinicians in enhancing the quality of life for people with intellectual disabilities who develop dementia. They offer clear guidance for assessment, diagnosis, interventions, and ongoing support. These revised guidelines were officially launched at the BPS conference on 10 June 2025. Link to guidelines: https://www.bps.org.uk/guideline/dementia-and-people-intellectual-disabilities-0

Treating patients well: principles for shared clinical practice in intellectual disabilities

Also, I wanted to share with you a great resource that has been published on the Academy of Medical Royal Colleges website to help support and guide doctors in all specialities on *Treating patients well: principles for shared clinical practice in intellectual disabilities.* This is going to be particularly helpful for colleagues who have not had much training in working with our patient group. A big thank you to Dr Mary Barrett who led on this work. Please do signpost colleagues to this link.

National Medicines Safety Improvement Programme

In other news, the National Medicines Safety Improvement Programme (MedSIP)—part of the National Patient Safety Strategy—will this year focus on reducing harm associated with psychotropic medications used for managing behaviour that challenges in people with learning disabilities. This commissioned programme will support selected Integrated Care Systems across England in taking a systemic approach to change. It will involve collaboration across NHS providers, social care, the voluntary sector, and those with lived experience. If you're interested in participating and shaping improvements in your service, please do get in touch Gill Gookey, Head of Medicines Safety Programme
Delivery: Gill.Gookey@nottingham.ac.uk

Group for ID psychiatrists who have lived experience of family/friends with ID

I wanted to share that within the Faculty we are setting up a group for ID psychiatrists who have a lived experience of family/friends with Intellectual Disability; their input and insights will really help strengthen the work undertaken by the Faculty. If interested in being part of this group, please get in touch Sam Tromans who is leading on this st386@leicester.ac.uk

Prof Bhaumik prize

Finally, I'm pleased to announce a new poster prize category at our faculty residential conference for SAS doctors and consultants within the first five years of their appointment. This award has been introduced in memory of the late Prof. Bhaumik, a national and international pioneer in the field of Intellectual Disability.

Save the date: Faculty conference

Save the date: Our next Autumn Faculty Conference will be held in Leicester on 7th & 8th October 2025. I look forward to seeing many of you there!

Warm regards,

Inder Sawhney
ID Faculty Chair

A Message from the Academic Secretary

Dr Samuel Tromans

Psychiatry of Intellectual Disability Spring Conference: 25th April 2025

I would like to thank all the psychiatrists across the Faculty who attended our Faculty of Psychiatry of Intellectual Disability Spring Conference event, held as a hybrid event at the Royal College of Psychiatrists.

The event was a huge success, with over 170 attendees both in-person and online, and a fantastic selection of expert talks covering a wide range of topics, including mental health law, epidemiology, epilepsy, treatment interventions, and medicines optimisation. I would like to also extend my thanks to all of our speakers who delivered such excellent talks, supported by our event feedback, with the conference receiving a mean average rating of 7.75 out of 10 among those who provided feedback.

It is wonderful for us as a Faculty to get together and discuss important issues, helping ensure that we can provide the best service possible to our patients and those who care for them.

I am also delighted to announce that our next Faculty Conference will be held at Voco Hotel in Leicester on Tuesday 7th to Wednesday 8th October. Further details, including the full programme and a booking link are available here: [Faculty of the Psychiatry of Intellectual Disability Conference 2025]

Finally, as our Chair Dr Indermeet Sawhney announced at the Spring Conference, our next Faculty Conference will mark the introduction of a new Faculty Prize, the Sabyasachi Bhaumik Prize, which will be open to SAS doctors and consultants within 5 years of obtaining their CCT. This project is in memory of the late Professor Sabyasachi Bhaumik, who was an instrumental figure in the Psychiatry of Intellectual Disability. Further details about our Faculty prizes are available here.

With best wishes,

Samuel Tromans
Academic Secretary

Higher Trainee Rep Update

Dr Abigail Swift
Faculty of ID Higher Trainee Rep

Happy belated Easter and I hope those with children have enjoyed the half term.

In the last 6 months, Liz sadly stepped down as the higher trainee rep but I've continued to do my best to represent higher trainees at the Executive ID Faculty committee meetings and hold regional higher trainee representative meetings.

The last executive committee meeting was held 24th April 2025 in London. We discussed various topical issues related to ID higher training of which I have updated your regional higher trainee representatives with further details who can forward these on.

If you a higher trainee representative but haven't received this email please email the list of higher trainee representatives below.

We've agreed within the regional representative meetings that we will increase the meetings to 3 times a year which is the same as the committee meetings.

The new dementia updated guidance for people with an intellectual disability is available for access. I'll be continuing to contribute to the working group around the updated guidance for behaviours that challenge for people with an intellectual disability.

Liam Embliss (ST5) has helpfully joined the ID executive committee as part of his role as the 'Sustainability Scholar'. He has been trying to raise the profile of sustainability within the ID Faculty which has translated into the ID Faculty considering who they bank with. Liam has also been involved in exploring the risk that heatwaves pose to people with ID and how to mitigate these. A particular highlight for Liam was to hold a focus group of ID service users to speak about heatwaves and hear their views on climate change.

The Sustainability Scholar post is an annual role and adverts for a September 2025 start date will come out in July 2025.

In other news, I will be stepping down from the role as higher trainee representative this month. I have thoroughly enjoyed my time in this role and all the opportunities it has brought.

I will be handing over to your new higher trainee representatives who are Ibrahim Younes and Irshad Hussain.

Ibrahim is an IMG who completed his core training in Wales. He is currently one of the ST5s in the Northwest of England.

Ibrahim has leadership experience as a BMA representative, ST representative, and Northwest Mentorship Program Lead. His ID Psychiatry placement prior to starting ST provided insights into varying training and service structures, driving his commitment to continuing the work to standardise and improve training quality across the UK.

Ibrahim also aims to foster better engagement by updating the regional representative list and leveraging social media platforms to promote the specialty.

He is dedicated to working with the college to address discrepancies in training and service availability, advancing the academic role of psychiatrists in intellectual disabilities to ultimately enhance patient care, building on the work of his predecessors.

Irshad is a higher trainee in Psychiatry of Learning disability (ST5), currently working at Cheshire and Wirral Partnership NHS Trust, and is passionate about advocating for the needs of people with learning disability and advancing the interests of the Faculty of ID Psychiatry at both regional and national levels. Over the past 18 months, he has served as the regional trainee representative for the North West England, where he has worked closely with his colleagues to raise trainee concerns and facilitate dialogues with senior stakeholders.

Irshad has a keen interest in maintaining high academic standards within training. He successfully led the organisation of the national ID trainee conference last year and hopes to help continue this tradition in the successive years. He currently coordinates the North West higher trainee academic programme.

Irshad is now hoping to contribute on a broader scale as the National Trainee Co-Representative for ID Psychiatry. He is especially passionate about addressing disparities in training experiences and resource allocations across regions and aims to work towards highlighting this more vocally. He values collaboration and mentorship, and he maintains strong professional relationships with members of the ID Faculty, past and present, who continue to support and guide him.

I wish them every success in the new role and will be handing over ideas for directions of work including plans for a further 'Welcome Event'.

If you are interested in applying for the Sustainability Scholar in the future role more information can be found here: https://www.rcpsych.ac.uk/improving-care/sustainability-and-mental-health/sustainability-scholars.

If you would like to find out more about Liam's experience, feel free to contact him- liam.embliss@nhs.net

Higher trainee representatives

Ibrahim Younes – ibrahim.younes1@nhs.net

Irshad Hussain- irshad.hussain2@nhs.net

Abigail Swift- Abigail.swift@wales.nhs.uk

Faculty Update

Long Term Segregation/ Seclusion Briefing Paper

By Dr Anupama Iyer

In November 2023 The Rt. Hon. Professor Baroness Hollins published a report entitled “My heart breaks - solitary confinement in hospital has no therapeutic benefit for people with a learning disability and autistic people” regarding people with an intellectual disability, and autistic people, who are detained in mental health and specialist learning disability hospitals. It was the culmination of the Independent Care (Education) and Treatment Review (IC (E) TR) programme which reviewed the care and treatment of 191 people who were detained in Long Term Segregation (LTS) between November 2019 and March 2023. The Review was commissioned in December 2019 by The Rt. Hon. Matt Hancock MP (the then Secretary of State for Health and Social Care), with Baroness Hollins appointed to oversee the programme.

The Royal College of Psychiatrists published a detailed response to this review in May 2024.

The College attended a roundtable with Baroness Hollins to discuss her report and the College response to it. It was agreed that the College could help with developing improved definitions for LTS and Seclusion and could make use of its quality networks to develop standards.

To take these actions forward the College set up a small working a group of psychiatrists largely from the College Intellectual Disabilities Faculty. Also, on the group are Dr Richard Latham (College MHA co-lead), Dr Dan Hayes (College Child and Adolescent Faculty), Safiya Jones (Policy and Influencing Manager at the College) and Thomas Rutherford (Policy Officer at the College).

This work applies to England. The College recognises that policy and practice vary across the respective nations of the UK.

The group is looking at the aspects outlined below:

- Alternative definitions for LTS and Seclusion to inform any proposed amendments to MHA and Code of Practice.
- Exceptions/Exclusions to LTS definitions not currently included in the Code of Practice.
- Review of existing Safeguards regarding LTS/Seclusion and recommendations for change as required

We are seeking your opinion regarding these two areas of especial importance to ID Psychiatry:

Alternative terminology suggestions for Long Term Segregation

The term “Long Term Segregation” focuses on time span and does not highlight that it is predicated by risks to others.

The term “segregation” is a non-neutral term which has acquired negative connotations over the year.

Do we need an alternative term to describe this “separation because of risks” such as risk related separation or risk related specialist support.

Exceptions and exclusions to the LTS definition

There are no current terms to describe the practice of patients being treated in bespoke, individualised settings either because of their own specific treatment needs or their choice.

These include:

- Therapeutic Segregation for non-risk related needs such a sensory needs.
- Patients choosing to isolate themselves.

- Patients being cared for in singleton placements within hospitals with their "own front door" and specialist staff teams within hospitals.
- Single Occupancy Care & Support within wards.
- Flexible use to manage behavioural distress.

Options appraisal for separation of "Therapeutic Segregation"/ LTS:

Option 1: No change suggested to the LTS definition/no demarcation of "Therapeutic segregation".

Option 2: "Therapeutic segregation" described under LTS Code of practice as an exception/ exclusion.

Option 3: Separate definitions for segregations due to risk and bespoke interventions with differing care plans, safeguards and outcome measures.

Option 4: Single occupancy care from the outset to manage risk to others, based on the model of care most suitable to an individual, following multidisciplinary assessment, and taking into account patient and family preference.

Please do let us have your comments and suggestions to inform this important issue.

Please email your feedback directly to Dr Anupama Iyer at agiyer@stah.org

Author Details

Dr Anupama Iyer
Elected member of the Executive Committee
and past Academic Secretary

An interview with...

The Staying Alive and Well Group

By Dr Sharna Bennett

The Learning from Lives and Deaths - people with a learning disability and autistic people (LeDeR) programme, aims to improve care for people with a learning disability and autism, reduce health inequalities and prevent unnecessary and early deaths. LeDeR reports investigate and learn from the deaths of people with learning disabilities and autistic people to help to improve care and reduce health inequalities.

I was privileged to interview Richard Keagen-Bull from the Staying Alive and Well Group. The group consists of people with learning disabilities, and their role includes communicating the LeDeR findings to a wider audience including people with learning disabilities. They represent the views of other people with learning disabilities on important issues and contribute to recommendations as a result of LeDeR findings.

The Staying Alive and Well Group

Richard Keagen-Bull

The Staying Alive and Well Group

Thank you Richard for agreeing to answer some questions about LeDeR for us. For those who aren't aware of LeDeR, how would you explain its purpose in a few short sentences?

LeDeR is a good way for everyone to see that some people with a learning disability die early and do not get good care. It shows everyone what and how to change things for the better.

Can you tell us more about the role of the Staying Alive and Well Group in supporting the LeDeR programme?

We (the Staying Alive and Well group) are a group of people with a learning disability who help with LeDeR. We understand what it all means because we live it; the issues that the report brings up affect us.

We also help make the big report easy for other people with a learning disability to understand. This is a difficult job that relies on a lot of hard work. We go through the report in a lot of detail.

What do you think is important about the work that the group do?

People with a learning disability (and people without a learning disability) need to know what goes on. They need to understand what happens to people and how to help and support people.

What are some of the main take home messages from LeDeR findings in recent years?

People with a learning disability die more than 20 years earlier than people without a learning disability and are about twice as likely to die an avoidable death. People were more likely to die from COVID-19.

We called the last report the 'spot the difference' report because we didn't notice much difference with previous years.

What changes and improvements have been made as a result of LeDeR findings?

Not enough. They still need to do a lot more.

What work still needs to be done to improve health and healthcare of people with LD and to reduce health inequalities?

The health of people with a learning disability should be prioritised. There should be more targets for services to improve care for people with a learning disability.

LeDeR should be made mandatory, and the reports should be published on time so that they have the biggest possible impact.

More people with a learning disability should have a voice, a voice which is heard, listened to and taken seriously.

How do you think people with a learning disability should be involved in improving services?

People with a learning disability should be involved from the start of the conversation, not just in bits and pieces, they should be involved from the start until the end. They should be properly paid for the work that they do.

People with a learning disability have the learning disability so they understand some of the questions and answers, they live it and have gone through it. They can tell people what it is really like and convince people to make changes.

Looking ahead, what are the Staying Alive and Well Groups main priorities over the next few years?

We want to make sure that things are being improved for people with a learning disability. We want less people to die and be neglected. We want more people to live healthy, fulfilled lives, just like anyone else.

Thank you very much for taking the time to answer our questions.

You can find the latest LeDeR report (published in November 2023) here: [LeDeR 2023 (2022 report)]

Author Details

Dr Sharna Bennett
ST5 in ID Psychiatry

ID Career Opportunities

Moving to the Other Side of the Table – From ID Consultant Psychiatrist to Tribunal Medical Member

By Dr Elizabeth Carmody

After more than 20 years as an Intellectual Disability (ID) consultant psychiatrist, I retired and took up the fee-paid roles of Tribunal medical member and Second Opinion Appointed Doctor (SOAD). As I had only ever practised in ID at consultant level, I had some anxieties about my knowledge and skills in other specialties - my training years seeming a long time ago! However, as I will outline [*over two articles*], the skills we develop as ID practitioners are eminently transferable to other roles and clinical areas.

In this article I will describe my experience as a First-Tier Tribunal (Mental Health) medical member, a role I was familiar with as a predominantly inpatient consultant in later years. The most striking aspect of this role has been how prevalent intellectual disability and / or developmental disability (ID / DD) is in this patient group. Whilst I have only very infrequently sat in a hearing where either of those diagnoses were relied on for detention, they formed part of the wider diagnostic formulation in more than a quarter of hearings (informal personal audit) and often contributed to the nature and degree of the disorder. In most cases the ID / DD was known and addressed by the clinical team and in cases where it was suspected, a Tribunal medical member can, where appropriate, focus their questioning to highlight where an intellectual or more commonly a developmental assessment might assist in identifying additional treatment and support needs. In that minority of cases where the diagnoses are relied on for detention, the expertise of an ID practitioner is warmly welcomed by other panel members who may have less experience in this area than in mainstream mental health. This expertise will continue to be relevant with the 2024 Mental Health Bill, CQC (2025), and arguably even more valuable – my experience has been that as training in ID / DD has increased in recent years, other panel members ask more informed questions of an ID medical member for clarification in the pre-hearing discussion. An explanation of the role of Care and Treatment Reviews (CTRs) and Independent CTRs for example, is a common topic. Consideration of capacity issues is another area where ID consultants have much to contribute.

Whilst expertise in the specific mental disorder is perhaps the most obvious area in which our skills are relevant, ID practitioners have much to offer in the consideration of the other detention criteria. In terms of risk, we are particularly attuned to risks to safety where vulnerability or suggestibility aspects are present but often overshadowed by risks to health and to others. When considering appropriate treatment, we are arguably more attuned to scrutinising the use of prn medication and restrictive practices in general. My experience as a Responsible Clinician of being questioned in CTRs has been invaluable in Tribunal practice, specifically exploring the extent of discharge planning and whether the assessment and treatment required could be delivered in a community setting instead.

The consideration of the detained person in the context of their families and wider support system is arguably more generally dealt with by the panel specialist member but is certainly an area very familiar to an ID clinician. My experience has been that the anxieties and concerns expressed by families, paid carers and others demonstrate shared themes across all specialities and can be elicited in much the same way as in ID practice. We are particularly aware of the need for additional safeguards, and I am very often the Tribunal panel member who asks about the role and contribution of advocacy services, IMHA or otherwise. Similarly, I have experienced no issues in interviewing a wide range of detained people, either in the pre-hearing examination (PHE) or indeed the hearing itself – any interview skills not routinely used in years of ID practice, such as eliciting more complex psychotic phenomenology, are readily reactivated and the enhanced communication skills required in day-to-day ID practice more than compensate.

Lastly, there is the teamworking aspect of Tribunal work. Teamwork is of course central to working in all mental health practice but due to the breadth of support needs required by people with ID, we are used to working with a wider range of professionals who necessarily have different perspectives and priorities than ours. It was a way of working that I greatly valued and enjoyed, particularly in an inpatient setting. The Tribunal panel is perhaps less readily obvious as a team but that is how it operates, and ID clinicians have much to contribute. In summary, the role of a Tribunal member draws on all the skills and expertise developed as an ID senior clinician and refocuses them in a challenging and stimulating way.

Reference

CQC (2025), *Monitoring the MHA in 2023/2024*, https://www.cqc.org.uk/publications/monitoring-mental-health-act/2023-2024

Author details

Elizabeth Carmody
Consultant Psychiatrist; Medical Member, First Tier Tribunal (Mental Health) & CQC Second Opinion Appointed Doctor (SOAD)

With thanks to Dr Joan Rutherford (Chief Medical Member of the Mental Health Tribunal Service).

Contact
chiefmedicalmember.rutherford@ejudiciary.net
to discuss applying for role.

Reflection

My experience of learning disability and autism-from the perspective of a family member and a trainee

By Dr Raheen Fatima

"Autism?? What does this mean?"

"Is he going to be ok?"

"Does this mean he is going to die?"

These questions can only show a small glimpse of a whole storm of questions battering my then ten-year-old mind. A close family member was diagnosed with autism at the age of four years by a visiting psychiatrist from abroad. Psychiatry was more popular in bigger cities like Lahore where people were diagnosed. The concept of mental health was, and to some degree still is, not very widely developed in small towns like where I grew up. The elders in the family did their best to answer my questions using the information they could collect from that single and time limited session with the doctor. I can imagine how many thoughts and questions would still be bubbling in their minds while explaining his diagnosis to me and other young minds in the family.

Growing up with an Autistic member of family with learning disability was different. There was not much in the way of follow ups with a specialist due to the travelling distance and disrupted continuity of care as the same practitioner would not be available at times suitable for us. There is no specialised Learning Disabilities service in my country, and the concept of special educational needs is largely limited to the physically disabled. Even though there is awareness around this topic through social media and TV programs, mental health, especially learning disability still attracts a huge amount of stigma.

A myriad of questions remained unanswered. Only with time and with hands on experience were we able to piece together the delayed motor milestones, speech delay, poor eye contact, the need for sameness, echolalia, poor perception of nearly everything and inability to engage in age-appropriate plays as being part and parcel of their learning disability. It was all frustrating and equally heartbreaking.

Watching them choose to remain indoors, occupying themselves with computer games and TV, struggling through teenage years and even being mistreated by neighbourhood children at times, it all took a toll on us in different ways. We could sense that even though they are constantly supported by us, a part of them appeared isolated and lonely. Having little to no access to specialist input, we settled on teamwork. We did all that we could to gently and persistently teach them just enough words so they could communicate their basic needs. Together we enabled them enough so they could look after their basic needs such as fetching water if thirsty.

A couple of years ago I applied for psychiatry training in Thames Valley Deanery. I dreaded a rotation in Learning Disability since my first day. I remember saying to my colleagues that I cannot do it as I will find it emotionally taxing. I was fearful that everything I would come across would hit home and destabilise my mental state. The day came when I received the job allocation email enlisting placements for CT2 year. I found my name next to the LD post. I could envision the worst outcome (i.e leaving training). Returning from maternity leave was another risk factor. I persuaded myself to have an initial meeting with my supervisor and explained how emotionally arduous this post is likely to be for me. I considered myself extremely lucky to have had a great supervisor who was incredibly supportive towards me throughout my rotation. I cannot thank her enough for helping me break this internal wall of emotional vulnerability down brick by brick, and ever so gently and subtly. She encouraged me to build confidence to take initiative in assessments. I learnt about the importance of building a rapport, picking up the non-verbal cues and forms of communication by reading between the lines and trying to understand things from the patient's perspective.

It was only through the power of incredible supervision that soon it all started to come naturally to me, and I felt more at ease with this cohort of patients. While doing out of hours shifts, I allowed some extra time if I was asked to see a patient from the Learning Disability ward and I found myself very comfortable doing the assessments. There is still a steep learning curve, and I believe it never stops.

During my Learning Disability placement, I saw the dedication and empathy of staff and multiple disciplines involved within the service. This filled me with admiration, valuable knowledge and experience. I had an opportunity to witness the support offered within the inpatient service as well. This covered nearly all aspects of patient's lives including personal care, social care, emotional care, support with residence, education, employment, seeking medical help, and support during crises to name a few. This amazing experience of witnessing this service in action has changed my perspective of learning disability as a specialty so much that I am determined to choose this as a specialty for higher training. When Professor Mahesh Odiyoor delivered a very interesting talk on "The I in a Team – leading with passion and purpose" to the attendees of National Intellectual Disability Psychiatry Trainee's Conference in November 2024, he posed a question "what is your why?". I believe that it is safe to say that I have found my why.

I did not realise when it became a part of me and I reflected on my conversations with my family, studying the patterns of my family member's behaviour together, discussing with them the challenging behaviour and possible underlying causes of this. I found myself helping them support with positive behavioural strategies in a better way. I feel at ease with myself as I am beginning to fulfil my previously lost role as a relative in a better way in this context. I do not wish to stop here. I hope to extend this within my hometown, providing psychoeducation around mental health issues, especially learning disabilities in the wider community, hoping to break barriers in seeking help and supporting people to become neurodiverse aware.

Important Note: Consent could not be obtained from the family member due to the nature and severity of their disability. However, consent has been obtained from their next of kin (their parents) for details of their illness to be used in this article for publication in the ID Newsletter.

Author details

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Oxford Healthcare NHS Foundation Trust

Clinical Debates

Dementia in Intellectual Disability: A Clinical Challenge Under Debate

By Je Ssy Low

Introduction

Dementia affects around one in five individuals with intellectual disability (ID) aged 65 or over, with even earlier onset in those with Down syndrome (1). As life expectancy increases due to improved healthcare, the demand for timely and tailored dementia care for people with ID is growing.

During a six-month placement in an ID service as a core psychiatry trainee, I came to appreciate how subtle changes in behaviour and functioning can signal the early stages of dementia. Yet these signs are easily misattributed or missed altogether. Reaching an accurate diagnosis often depends not just on structured tools, but on clinical judgement, awareness of baseline functioning, and collaboration across a multidisciplinary team.

The Current Debate: Are We Getting the Diagnosis Right?

Diagnosing dementia in individuals with ID is clinically complex, with multiple factors fuelling continued uncertainty and discussion:

- Symptom overlap: The clinical features of dementia—such as memory decline, disorientation, and behavioural change, can closely resemble the long-standing cognitive and adaptive limitations seen in ID. This overlap often obscures early signs of dementia, making timely diagnosis difficult.
- Communication barriers: People with moderate-to-severe ID may struggle to report memory problems, confusion, or emotional changes clearly, limiting the effectiveness of standard assessments.
- Limited awareness among clinicians and carers: Subtle behavioural or functional changes may go unnoticed or be wrongly attributed to the underlying ID.
- Diagnostic overshadowing: New symptoms such as low mood or withdrawal may be mistaken for a person’s baseline or other mental health disorder, delaying further investigation.

This raises an important question:

Are current clinical practices sufficient to ensure early and accurate dementia diagnosis in individuals with ID?

Real-Life Challenges

In clinical settings, signs of dementia in people with ID often emerge gradually. One individual I reviewed showed a progressive loss of interest in her favourite activities and became increasingly passive. This change was subtle and could easily have been misinterpreted as depression. In another case, visual hallucinations were suspected, but the person’s mild to moderate ID made it difficult to obtain a reliable history. A tendency to agree with leading questions — known as suggestibility – is a recognised communication pattern in this population and may unintentionally influence clinical impressions if not approached with care.

Communication limitations, such as reduced verbal ability or comprehension, can significantly complicate assessments. In these cases, clinicians rely heavily on collateral information from carers and support staff. However, in services with shift-based staffing, continuity can be inconsistent. Different staff may have varying familiarity with the individual, leading to fragmented or conflicting reports. This highlights the importance of regular team reviews, consistent record-keeping, and open communication to support sound clinical decision-making.

Structured Tools: Useful, not standalone

Tools such as the DLD (Dementia Questionnaire for People with Learning Disabilities), CAMDEX-DS (for those with Down syndrome), and DMR/DMRIID provide valuable structure to assessments (2). However, these must always be interpreted in the context of the person's baseline functioning; a checklist alone is never sufficient.

What Needs to Change

In light of these ongoing challenges, I believe several key changes could help improve the way dementia is recognised and supported in individuals with ID:

- Utilise the national guidelines tailored to the specific needs of this population.
- Improve training for healthcare professionals, carers and families to help identify early signs.
- A shift towards long-term, person-centred assessment, supported by regular documentation.
- Bringing ID and dementia services together to make sure people get the right care at the right time.
- Strengthening post-diagnostic care to ensure consistent emotional, behavioural, and practical support beyond the point of diagnosis.
- Greater ethical awareness**:** Timely diagnosis promotes dignity and supported autonomy, enabling individuals and families to plan personalised care.

Conclusion

The question of whether we are accurately diagnosing dementia in individuals with ID remains a subject of ongoing debate. While structured assessment tools, input from multidisciplinary professionals, and advances in neuroimaging have improved our ability to detect cognitive decline, several challenges still complicate the process.

Based on my clinical placement, accurate diagnosis requires more than cognitive scores. It demands clinical curiosity, a team-based approach, and an in-depth understanding of the person's unique history and behaviour. Carers and families are critical to recognising early signs of dementia. Without this shared understanding, dementia can easily be missed or misinterpreted.

Ultimately, this debate is about equity. Are we providing people with ID the same standard of dementia care and early detection as we do for the general population? Moving forward, we must commit to delivering consistent, compassionate, and evidence-based care to ensure this often-overlooked group receives the recognition and support they deserve.

Guidance on the assessment, diagnosis, interventions and support of people with intellectual disabilities who develop dementia:

https://www.bps.org.uk/guideline/dementia-and-people-intellectual-disabilities-0

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Audit

An evaluation of anticholinergic burden in patients admitted on Learning Disability Assessment and Treatment Units

By Dr Rhyanna Morris and Dr Irshad Hussain

Background

People with learning disabilities (LD) often experience complex health needs, including higher rates of psychiatric and neurological conditions, leading to polypharmacy and an increased risk of adverse effects. Anticholinergic medications are associated with adverse effects such as cognitive decline, falls, constipation, urinary retention, and increased mortality risk (Bishara et al, 2021) in the general population, particularly older adults. People with LD may be particularly vulnerable due to pre-existing cognitive deficits.

Although more LD-specific research is needed to develop targeted guidelines and intervention strategies in people with LD, there is enough indirect evidence to warrant concern about anticholinergic drug use in people with LD, particularly regarding cognitive and functional impairment (Ward et al, 2021).

This project aimed to look at the prevailing prescription of medications with anticholinergic effects, to stratify individual risk based on anticholinergic burden score, and explore possible interventions to minimise the risk. We have presented selective findings from the project undertaken.

Aims and Objectives

- To assess and attempt to quantify the prescription patterns of anticholinergic medications in people with LD in Assessment and Treatment Units (ATUs).
- To recommend actions based on the findings.

Methodology

Population:

Patients admitted on Eastway and Greenways ATUs (Cheshire and Wirral Partnership NHS Foundation Trust) during the period, February 2024 - February 2025.

Data Collection

Patient were identified using a spreadsheet used by staff to hold admission data.

The data was obtained using information available on the Trust electronic patient record.

Anticholinergic burden (ACB) scores before admission and during admission/ at discharge were calculated using both the ACB calculator and Medichec tools that are accessible online.

The data was charted on to a ‘Data Collection Tool’ designed for this project.

Data Analysis

We used scores computed by ACB calculator to analyse our results but also computed scores through Medichec for reference. The ACB calculator uses anticholinergic cognitive burden scale and the German anticholinergic burden scale (GABS) to calculate the scores.

Results

A total of 13 patients were evaluated in this project.

Table 1. Analysis of results

	Total no. meds during admission/ at discharge	No. of medications with ACB >3	No. of medications with 0<ACB<3	Total ACB Score before Admission	Total ACB Score at during admission/ on discharge	No. of new meds prescribed	No. of new meds with ACB >0
Mean	9.2	0.8	4.0	5.6	6.3	4.8	1.8
Median	9.0	1.0	4.0	5.0	5.0	4.0	2.0
Mode	12.0	0.0	4.0	8.0	4.0	4.0	0.0

The mean total number of medications prescribed during admission/ at discharge for the evaluated patient cohort was 9.2 and the median total number for the same was 9.0. Fewer than one medication had an ACB score exceeding 3 (mean = 0.8, median = 1.0)). The number of medications with an ACB score greater than 0 but less than 3 was 4 (mean = 4.0, median = 4.0)

This probably suggests that medications with low to moderate ACB scores (0<ACB<3) contribute predominantly to the overall ACB within our patient cohort.

The mean ACB score before admission was 5.6, rising to 6.3 on discharge/ during admission (Table 1). However, the median score for the same remained unchanged at 5.0. Given the limited sample size, the median score serves as a more robust and representative measure of central tendency. Since the data is not normally distributed, we considered Wilcoxon Signed Rank test; the results did not have any statistical significance (p=0.08447). Using a less conservative threshold (α = 0.10, compared to the normal α = 0.5), there are marginally significant differences and an increase in inpatient ACB.

The median number of new medications introduced with an ACB score > 0 was 2.

Figure 1. Comparison of ACB scores (pre-admission vs inpatient)

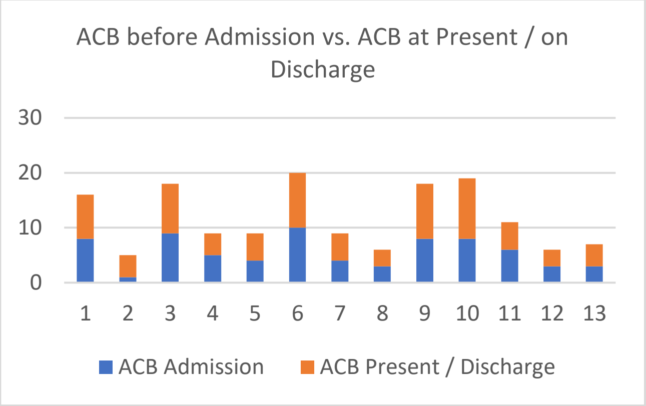


Figure 2. Number of new medications started as an inpatient and number of those with ACB >0.

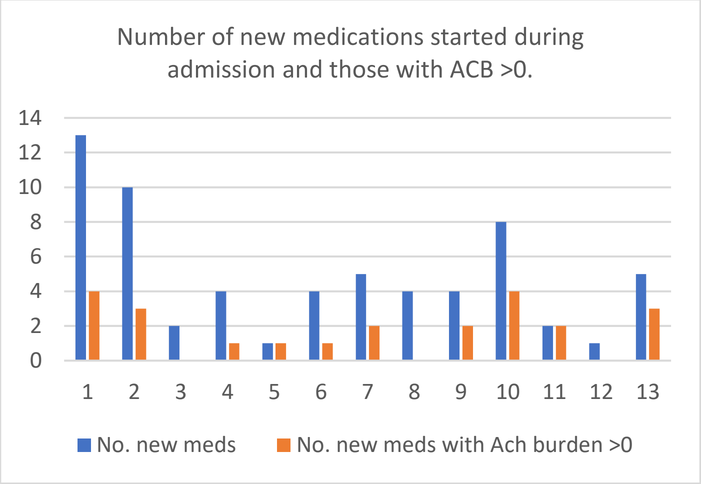
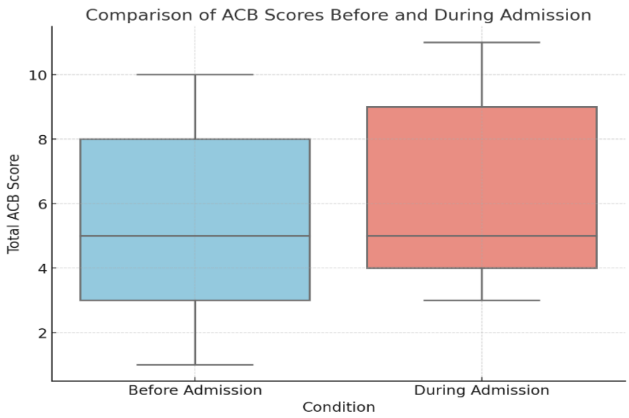


Figure 3. Boxplot: Comparison of ACB Scores Before (prior to admission) and During Admission (at present/ at discharge)



Discussion

Although the study does not highlight any statistically significant change in ACB scores during inpatient admissions (except when using a less conservative significance level) of this small patient cohort, the anticipated clinical risks of a high ACB, including morbidity and mortality, highlights the importance of this evaluation (which forms part of a more detailed audit project). It must be taken into consideration that LD patients respond to medications differently and consequently may have a lower threshold to side effects, which possibly could lead their high ACB scores to be a significant risk. An interesting piece of research, by Salahudeen et al., discusses the cumulative burden of anticholinergic medications having a direct negative impact on cognition, reduced physical function, and increased risk of mortality.

Again, when using a less conservative significance level for median scores, one reason why ACB scores might appear to rise during admission is that patients would be presenting with serious mental illnesses or challenging behaviours (that necessitated the admission in the first place) and this warranted medical treatment with psychotropics, many of which have anticholinergic properties. Another explanation would be that following admission, there would be a greater likelihood of identifying physical health issues (hypersalivation, colic, etc) leading to prescription of medication with higher ACB scores and without alternatives. Despite these explanations, the authors would recommend that due consideration be given to ACB scores of individual drugs when prescribing. Last but not the least, the authors identified issues with the ACB tool itself; for example, the tool allocates positive scores to medications such as benzodiazepines (in contrast to other tools such as medichec) which would be inconsistent with the mechanism of action of these drugs.

A limitation of this evaluation study is that it only analyses ATU inpatients (currently admitted or recently discharged) at CWP, which creates a bias in terms of sampling/ ascertainment. This limits the generalisability of the findings. As well as this, tracking medication changes post-discharge may be challenging due to transitions in care settings.

Another limitation of this evaluation is based on the fact that no available ACB score calculating tool takes into account doses and routes of medication (to the best of our knowledge). As well as this, we have not found any evidence the tool used here (or any other tool) is validated for use in the LD population.

Recommendations

Future studies on similar themes should involve a larger cohort, for example, service users with LD open to all inpatient and community teams across the Trust.

Regular monitoring of response to medications with high ACB, and if minimal therapeutic effect, re-evaluate risk/benefit and consider an alternative with a lower ACB.

To conduct a more thorough literature review on use of ACB calculation tools for people with LD, and explore developing a tool that is validated for people with LD.

In the long-term, consider if an ACB tool can be formulated that takes into account dosage and route of medications

Conclusion

Our evaluation reveals a clear concern: people with learning disabilities are often prescribed multiple medications with anticholinergic properties, leading to a potentially high anticholinergic burden—even before admission. While our small sample didn't yield statistically significant changes in ACB scores during admission, the clinical implications remain worrying, particularly given this population's increased sensitivity to cognitive and functional side effects.

More importantly, this project exposed several key gaps in our current approach. The tools we rely on to assess ACB were not developed or validated for people with learning disabilities. They don't account for medication dose or route effects—and may even score medications inconsistently, such as attributing ACB points to drugs like benzodiazepines against their pharmacological profile.

This highlights a need to explore, and in the absence of one, develop and validate an ACB tool specifically for the LD population—one that reflects their unique vulnerabilities and treatment needs.

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In the Media

Cultural Reflections on Intellectual Disability in Egyptian Cinema: A Review of "Mabrouk wa Bolbol"

By Dr. Ibrahim Younes

Media portrayals offer crucial insight into our understanding of illness and disability. It is a mirror of societal preconceptions and attitudes towards people with disability and is a powerful tool to counteract stigma. In my recent re-viewing of the Egyptian film "Mabrouk wa Bolbol" (مبروك و بلبل), I was particularly drawn to how it unpacks family relationships and cultural attitudes that shape the lives of people with Intellectual Disability (ID). The film offered a glimpse of Egyptian cultural and societal norms, whilst raising questions of how disability is represented, both on screen and within family in contemporary Egyptian society.

"Mabrouk wa Bolbol" explores society's understanding of a man's role and how this can be affected by disability. The story follows a man with ID whose life on a rural farm becomes a canvas to display themes of identity, family duty, and resilience. One fascinating element is the protagonist's name, "Mabrouk," which means "Blessed" in Arabic. While the name suggests hope, the story reveals a harsher reality. Mabrouk's habit of wearing identification—symbolically "keeping his ID around his neck"—serves as protection in a world where he constantly risks being lost, both literally and figuratively.

The film explores psychological development amid loss. The main character's behaviour, which swings from joy to distress, reflects real-life challenges such as grief and the struggle for self-identity. Mabrouk's deep attachment to his late mother which offers a source of comfort and protection for him, is a powerful portrayal. Her death triggers emotional disturbances in him; he shows grief, anger and tantrums, which appears to strike an emotional chord with audience. This loss leads him to try filling the void by seeking replacement mother figures. In several touching scenes, he struggles when his sister takes on a caregiving role: despite her efforts, he knows she cannot replace his mother.

Another key theme is his changing role within the family. Mabrouk becomes a substitute male figure after his father's absence yet remains dependent like a child. His relationship with his sister shows a complex mix of care, replacement of lost parental support, and sometimes the unintended burden of overprotection.

The film also explores relationships with characters like Bolbol (meaning "Nightingale"), his childhood friend. Initially, Bolbol appears accepting, but as her life takes a controversial turn—eventually involving sex work—the story shifts. In one emotional scene near a graveyard, Mabrouk's attempt to reconnect with her is both tender yet unsettling. This shows how ingrained broader social attitudes toward sexuality transcends everyone. His protective stance when defending his sister against an abusive husband further emphasizes his role as a male protagonist in Egyptian society. Such depictions highlight that within traditional Egyptian society, a ‘man’ with intellectual disability is often placed in roles requiring emotional strength and support for others; even when these roles come at personal cost.

At its heart, the film is about the search for identity. Mabrouk is caught between childhood innocence and adult expectations, especially after losing his mother. His behaviour—showing both independence and unresolved grief; illustrates the internal conflict of wanting to reclaim his secure past whilst facing adult responsibilities. While the film tries to offer a hopeful ending, it sometimes falls into melodrama.

The culturally specific portrayal of disability from sentimental moments to the depiction of family duty; reveals underlying social attitudes. For instance, the film's exploration of relationships mirrors the importance of balanced representations of disability.

The film's depiction of intellectual disability sometimes relies on stereotypes by overemphasizing a "need to be saved" narrative. However, its emotional honesty and the way it challenges viewers to think about identity, loss, and cultural expectations is valuable. I couldn't ignore how cultural values interact with religious and traditional norms. In societies where family honor and parental duty are paramount, a person with intellectual disability may be simultaneously cherished and marginalized; a contradiction the film skillfully illustrates.

"Mabrouk Wa Bolbol" is a multifaceted work that uses personal tragedy and complex relationships to comment on broader cultural and psychological issues. Its symbolic use of a name suggesting blessing amid suffering, its exploration of maternal loss, and its presentation of conflicting social roles all contribute to a rich portrayal of life with an intellectual disability. It provides both an emotional journey and a basis for reflection about how disability is understood across different cultural landscapes.

I end by opening up this question to the reader - How can media help improve the community’s attitudes and understanding of people with disability?

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Conference Watch

Psychiatry of Intellectual Disability Spring Conference 25th April 2025

By Somya Pandey and Meghna Nair

Introduction

We - Somya, a SAS doctor in ID psychiatry, and Meghna, a medical student - are writing this piece together to share our reflections from the Spring Conference 2025. Though we come from different backgrounds and stages in our medical careers, our shared interest in intellectual disability brought us together.

After careful consideration, we decided to provide free-flowing, separate reflections to offer insight into how a SAS doctor and a medical student see and learn through different lenses, shaped by their levels of exposure and expertise.

Reflections

Somya Pandey, SAS Doctor

The Mental Health Bill: Implications for People with ID

Mental Health Act detentions in the UK, especially for people with intellectual disabilities, have been under scrutiny for a long time - and for the right reasons. This talk got me thinking about my most complex patients and the challenges my team has been facing in facilitating their discharge from hospital. Professor John Taylor talked about the risks associated with the proposed changes in the Bill and the burden on community services. While I agree people with autism and ID can 'get stuck' in the system, I do not believe the answer is to implement restrictions on their detention without taking a formal stock of the services available for them in the community.

The PETAL Programme for Aggressive Challenging Behaviour

Professor Angela Hassiotis highlighted the importance of addressing challenging behaviour, particularly within the community, where about 10% of individuals with ID exhibit aggressive behaviours. As she discussed the PETAL Programme, which includes seven key components including carer wellbeing and environmental factors. I found myself reflecting on how this structured approach could be applied in our own care environments. Along with the benefits of the therapy programme observed in the cohort, Prof Angela also described the challenges faced—such as fluctuating motivation levels and changes in carers between sessions—which invited the need for innovative and creative approaches to delivering PETAL. What had the most impact on me was learning about the content of the individual modules, which opened my mind to the possibilities of how we might address similar challenges on our ward with some of our most complex patients.

Multi-component anxiety management programme (M-CAMP-ID) versus treatment as usual (TAU) for people with intellectual disability: a feasibility mixed methods quasi-experimental study

Listening to Daniel Acton and Professor Sujeet Jaydeokar's talk on the M-CAMP-ID programme reminded me of the numerous patients I've seen who struggle with anxiety but often lack access to specialized interventions. What struck me was how the M-CAMP-ID programme allowed patients to feel 'in control'—something we often forget to offer. This has challenged me to consider how I can incorporate elements of control and agency into the treatments I provide.

Insights from the 2022 LeDeR report

After learning about the LeDeR report and considering the findings presented by Dr Rory Sheehan, I was struck by the reality of avoidable deaths in the learning disability population, and it made me reflect on the quality of care we provide. This data highlights the gap in healthcare equity that still exists, and I feel compelled to take a more active role in advocating for systemic change within my practice. The fact that so many deaths were preventable makes me wonder what further steps I can take, both professionally and personally, to ensure better healthcare outcomes for this vulnerable group.

Systematic Review: Autism in the Justice System

Working with individuals with autism and intellectual disabilities, I've witnessed first-hand how challenging it can be for them having had difficult experiences within the criminal justice system. Their heightened vulnerability to unfair treatment, especially without a proper diagnosis, made me think about the gaps in the system. The evidence from this review by Verity Chester pushed me to consider how much more could be done in terms of training and autism screening.

Meghna Nair, Medical Student

Criminal Justice and ID: Dr Jane McCarthy

With limited exposure to forensic ID psychiatry in university, Dr McCarthy's talk was especially impactful. It made me realise how many individuals with undiagnosed ID slip through the cracks in the criminal justice system. The continued lack of adequate screening in prisons is deeply concerning, particularly in environments not designed with neurodiversity in mind. It's an area I'm now keen to explore further.

Step Together: Epilepsy in Intellectual Disability

Tom Shillito and Hafsha Ali's talk on epilepsy in ID was particularly personal for me. As a carer for someone with profound ID and epilepsy, I really felt the urgency behind the speakers' message, having first-hand experience on how limited services can be. SUDEP is a serious and often under-recognised issue, and while the statistics were heartbreaking, it was empowering to hear that these deaths are preventable. The benchmarking toolkit presented felt like a genuine and practical step forward in tackling these gaps.

Deprescribing: A Behavioural Science Approach

As I'm currently working on a university project on STOMP, I found the session on deprescribing particularly engaging. Hearing it discussed from a behavioural science perspective was especially interesting. Sion Scott's points about how training alone doesn't lead to real-world change really resonated with me, and Shiva Fouladi-Nashta's real-life case example brought the discussion to life. It was inspiring to see research being implemented in a way that directly improves patient care, and it made me even more passionate about this area.

BEAMS-ID: Behavioural Interventions for Anxiety

Having explored challenging behaviour in ID through my own research, I've come to appreciate how behaviours that are often dismissed as 'challenging' can in fact be manifestations of underlying anxiety and unmet emotional needs. I really valued this perspective, which reframes these behaviours as meaningful expressions rather than symptoms to manage. The BEAMS-ID talk brought this to life. Hearing directly from patients about how the intervention helped reduce their anxiety made everything feel more real and human, and reinforced just how important it is to listen to these voices. It gave me hope that we might begin to normalise these kinds of psychological interventions across services, rather than treating them as specialist extras.

Conclusion

Somya's thoughts - Attending this conference wasn't just a break from routine; it was a much-needed spark that reignited my motivation to plan and strive for a better world—for all of us. As I walked out of the room, I felt a sense of contentment, with my inner deep thinker piqued. I found myself reflecting on my future as a Consultant—and how much potential I hold to drive change within the system, especially with the insights I now carry.

Meghna's thoughts - I left this conference feeling incredibly inspired. As a student, my perspective is still developing; more observational than hands-on, but no less curious. Attending the talks deepened my understanding of both the clinical and wider systemic issues involved in caring for people with intellectual disabilities. But what moved me most was being surrounded by so many like-minded people who genuinely care about this community. Sometimes in medical school, it can feel like these issues are sidelined - but here, they were front and centre. It confirmed for me that ID psychiatry is where I see myself in the future.

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Conference Watch

Child & Adolescent Intellectual Disability Psychiatry Network (CAIDPN) Conference 2025

By Selin Aktan

This year's CAIDPN conference was held at the spectacular National Gallery of Scotland in the heart of Edinburgh – an inspiring venue for two days of wonderful speakers presenting informative and thought-provoking sessions on the latest research as well as clinical practice with sleep and movement disorders, in children and young people with intellectual disabilities.

The conference theme 'Beyond Words: An Exploration of The Mental Health of Children and Young People with Severe and Profound Learning Disabilities' was reflected powerfully in the opening day's lineup. Attendees were treated to a series of compelling talks that delved into complex and often under-represented topics. The sessions that stood out for me and even led to some emotional moments included: 1. Dr Sarah Crawford discussing the portrayal of children with severe and profound ID in the media, 2. Elaine Davis (from the charity Kindred) on working with families of children with complex needs in their early days in the Royal Hospital for Children and Young people, and 3. Pat Graham and Danielle Shull (from the charity PAMIS) focusing on bereavement and loss and how young people with profound and multiple disabilities and their families/carers are supported.

I would recommend everyone watch the television series "There She Goes", based on real life experiences. The series follows the story of Rosie, a nine-year-old girl with severe learning disabilities, offering a rare and honest portrayal of family life. Despite not being previously aware of the show, I'll be watching it as soon as possible—and suggesting it to families in clinic who may find comfort and connection in its narrative.

From my clinical experience so far, the grief process around having a child with disabilities is something that comes up during assessments more frequently than one might think, but unfortunately remains a taboo subject that either families do not want to admit to or feel judged by clinicians, no matter how considered the discussion is phrased. A show like "There She Goes" could act as a catalyst for more open, supportive discussions between clinicians and families about the chronic sorrow, which in turn could help with the overall quality of life of the young person and their family.

Overall, the conference was well-organised and brilliant. Furthermore, it was a very supportive event for trainees who might be considering a career in CAMHS-ID as it provides ample opportunities to discover and discuss career development with highly experienced consultants. Throughout my training as a dual trainee in Child & Adolescent and Intellectual Disability Psychiatry, I have had the chance to experience working in services for both young people and adults. This has provided me insight about outcomes in adult life. I believe by providing timely and adequate interventions and support, we can create long-lasting changes and improve the quality of life of people with ID. CAMHS-ID services are in a perfect position to deliver such interventions and support. In addition, I believe working with people with ID is a highly fulfilling career option, and meeting people at this conference was testament to this.

For those trainees who missed this year's event in beautiful Edinburgh—don't worry! Next year's conference will be held in London, and I highly encourage you to attend. Finally, I would like to thank CAIDPN and ACAMH for giving me the opportunity to attend this year's conference.

Child & Adolescent Intellectual Disability Psychiatry Network (CAIDPN)

By Dr Ashley Liew

CAIDPN is a friendly network of over 250 Psychiatrists and Paediatricians who are passionate about supporting the mental health of children and young people with intellectual disabilities. It provides peer support for issues related to clinical care, service development, training, and academic research. CAIDPN is hosted by the Association of Child & Adolescent Mental Health (ACAMH) and is represented on the Executive Committees of both the Faculties of Child & Adolescent Psychiatry and Psychiatry of Intellectual Disability at the Royal College of Psychiatrists.

CAIDPN has a buzzing online forum packed with useful resources, plus two great annual events: a two-day in-person residential conference each May and a one-day online meeting every November. Are you a Resident Doctor interested in CAMHS-ID? Good news—we offer trainee bursaries to support you attending the residential conference (just like Dr Aktan did this year).

Want to join or find out more? Drop an email to mark.lovell@nhs.net

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Professor Joan Bicknell Medical Student Essay Prize Winner

Lessons from my discussions with autistic people

By Ben Erin

The first time I was involved in the care of a patient with a learning disability was through my work as a healthcare assistant. The patient, whom I will refer to as Sally, was a young woman seated comfortably in her hospital bed, with her nurse sat beside her. Sally, a non-speaking autistic person with a learning disability, frequently visited the hospital due to physical health issues. Although Sally often smiled at me and appeared cheerful, I felt a sense of discomfort. I was unsure how to communicate with her and subsequently provide her the best quality care. Her nurse, however, seemed to instinctively understand Sally's needs, calmly guiding the process as we assisted with her hygiene. Observing their ease with one another stood in stark contrast to my own anxiety, which I couldn't shake throughout the interaction. I couldn't rid myself of a lingering sense of guilt for feeling this way. Like many others in healthcare, I chose this profession to help people, but in this situation, I felt unequipped to support a patient whose needs were unfamiliar to me.

For me, communication skills always feel like the most important tool in a physician's practice. I have always felt particularly engaged in sessions focused on improving patient interaction and enjoyed simulation sessions with patient educators or actors. I found fulfilment in hearing patients' stories and working to meet their needs. Yet, in this interaction with Sally, I felt clueless. I had no idea how to communicate with her. How could I understand her needs? How could I build trust? How could I be more like her nurse—empathetic without being patronising, calm without being detached? This experience left me questioning my own abilities and approach to caring for patients with learning disabilities.

Introduction

In my fourth year at Brighton & Sussex Medical School, I engaged in a module called Time for Autism (TfA) (1). This education programme aims to transform healthcare for autistic people by increasing the knowledge and understanding of future doctors. It encourages students to rethink their perceptions surrounding autism and reflect on how misconceptions and stereotypes impact autistic patients and their experiences in healthcare. The module emphasises the diversity within the autistic spectrum and challenges students to think about how best to support autistic patients.

It is important to clarify that the module focused on autism, which is not synonymous with a learning disability. A learning disability is defined as a neurodevelopmental condition characterised by significant limitations in intellectual functioning and adaptive behaviour, beginning in the developmental period (2). Autism, on the other hand, is a neurodevelopmental difference that affects how people communicate and interact with the world (3). Most autistic people do not have a cooccurring learning disability (4), but learning disabilities co-occur at higher rates in autistic people (5). The TfA module included discussions around supporting autistic people with and without co-occurring learning disabilities, and I believe that many of the learning points I gained from this module are equally applicable to autistic patients with and without learning disabilities.

The Time for Autism module was inspiring and enlightening. I remember being shocked when taught about the health disparities experienced by autistic patients. Autistic patients have a lower life expectancy and experience more avoidable deaths than the general population (6). One UK-based study found the life expectancy for autistic people with intellectual disability was 7.28 years lower than the general population (7).

Additionally, studies suggest the rate of mental health problems in people with a learning disability is double that of the general population (8,9). Furthermore, adults with learning disabilities are at significantly higher risk of having a wide range of physical health conditions, including epilepsy, constipation, visual impairment, hearing impairment, and asthma (10). One reason behind these disparities is the overwhelming and challenging nature of accessing healthcare, which often leads to avoidance and, subsequently, worsened health outcomes (11–13). A major barrier to healthcare for autistic patients, with and without learning disabilities, is that they often feel misunderstood and stigmatised in healthcare settings (11–13). These negative experiences of healthcare can be due to poor inter-personal communication with healthcare professionals, which contributes to disparities in their care (14,15). When this information was delivered to me, it didn't sit easily. As someone who has spoken to many healthcare professionals, I sensed that no one would intentionally want to stigmatise a patient. But this module hammered home the fact that misunderstanding, intentional or not, has serious downstream impacts on health. Given my prior interest in communication skills, this sparked a strong desire to pursue my own research on the topic.

Inspired by the TfA module's emphasis on improving communication with autistic patients, I sought to explore this further through my own research. I joined the University of Sussex Junior Research Associate (JRA) scheme, where I carried out a project focusing on autistic patients' experiences of stigmatising language in the NHS. I recruited nine autistic individuals, some of whom had co-occurring learning disabilities, and interviewed them to explore their experiences of stigmatising language in the NHS and potential strategies to prevent such language in the future. The insights from this study fundamentally shifted my approach to the care of autistic patients. While autism is distinct from learning disability, some participants in my study had a learning disability, and I believe the lessons I learned are applicable to both autistic people with and without learning disabilities. The following section will delve into five key lessons I learned from my conversations with autistic people during my research, particularly how these insights shaped my approach to improving communication with autistic patients with learning disabilities. I will integrate direct quotations from the participants of my study as well as relevant literature to support these lessons.

1) All behaviour is communication

One key lesson I have learned from my discussions with autistic people is that all behaviour is a form of communication. Many participants shared their frustration at being misunderstood or labelled as "difficult" by doctors due to differences in communication styles or emotional regulation. This misunderstanding may stem from a lack of awareness among healthcare professionals about the diverse ways autistic individuals express their needs and emotions (11).

"[autism is] seen that it is difficulty, something that doctors and nurses don't want to have to deal with it because it's difficult"

As a medical student, I have often observed patients with complex behavioural needs in hospital wards. Their behaviours, including heightened emotional responses, physical withdrawal and difficulty engaging with the care team, can understandably cause frustration among healthcare teams managing demanding workloads. While such frustration is human, it underscores the importance of reframing behaviours not as obstacles but as meaningful expressions of need or distress.

For example, when a patient becomes emotionally dysregulated, it may be a sign of underlying distress, such as sensory overload, unaddressed pain, or anxiety about an unfamiliar environment (16). Similarly, behaviours like withdrawal or a refusal to engage may reflect overstimulation or a need for clearer communication. An often-overlooked phenomenon is situational mutism, where individuals temporarily lose the ability to speak due to heightened anxiety or sensory overwhelm (15). Recognising such responses as communication, rather than as a lack of cooperation, will allow me to better address the root cause of the behaviour when working as a doctor.

Failing to recognise behaviour as communication also risks diagnostic overshadowing—the assumption that a patient's behaviours are solely related to their autism or learning disability rather than being symptoms of an underlying medical condition (17). This can lead to delayed or missed diagnoses in patients with learning disabilities, putting their health at risk (17). As a future clinician, I will strive to pay close attention to behavioural changes, interpreting them as insights into a patient's physical condition or emotional state. Furthermore, to truly meet the needs of autistic patients, I must also recognise and respect patient's unique insights into their own needs.

2) The patient is the expert on their own needs

The participants of my study often encountered stigmatising language when healthcare professionals failed to recognise them as the experts in their own needs. Many participants reflected on how the language used to describe their challenges felt reductive or dismissive, often shaped by assumptions rather than active listening. For instance, healthcare professionals would sometimes adopt infantilising language after learning of a patient's autism diagnosis, or they would use terms such as "low functioning autistic person", which participants described as stigmatising and deeply upsetting.

"But during some instances some professionals have used some really condescending words and they have made me mistrust the process"

"'a low functioning autistic person'... they should use more accepting and friendly words according to me because that doesn't really define my challenges"

These reflections made me reflect on the importance of not making assumptions when working with patients with learning disabilities. Instead, I must remain open-minded, allowing patients themselves to guide me on their needs. My role as a healthcare professional is not to assume, but to listen. Patients are the experts in their own experiences, and it is my responsibility to respect that expertise by creating a space for open, compassionate communication. Failing to do so risks making patients feel misunderstood and undermining their autonomy. While respecting the patient's expertise is crucial, it is also important to address the systemic and environmental factors that exacerbate their challenges in healthcare settings.

3) The importance of control

Another key theme that emerged from my discussions was the importance of ensuring the patient feels in control. Participants described healthcare as an inherently overwhelming and disempowering environment. The sensory environment of a hospital is often overstimulating for autistic patients due to its typically busy, noisy, and brightly lit nature (18). This, combined with the inherent vulnerability of being unwell, can transform healthcare into a distressing experience. Control may be an essential factor in making healthcare more manageable for autistic patients (15,19).

"[healthcare is overwhelming] with the people speaking, and the phones going, and the movement, and the chairs, and the lights... I'm trapped. I can't say anything."

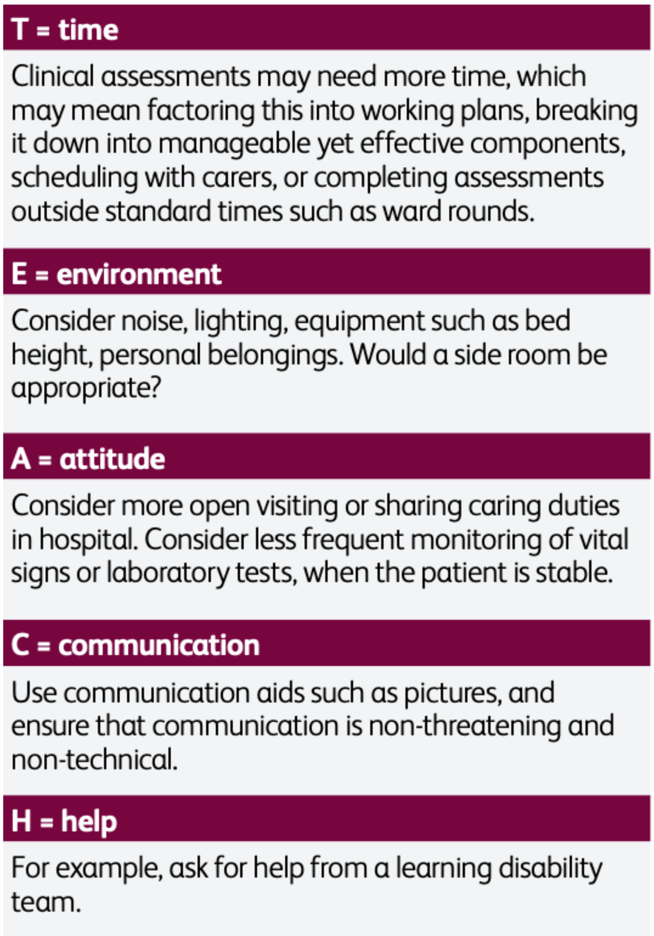
"[Providing control] it's asking about how they can make you feel comfortable"

Participants stressed the need for healthcare providers to recognise the inherent power dynamics of the patient-provider relationship and work to reduce this imbalance. One of the most effective ways to do this is by avoiding assumptions and instead actively inviting patients to articulate their needs and preferences. I believe empowering patients to advocate for themselves will form trust, reduce feelings of overwhelm, and form a partnership in care. This also involves using clear language when communicating, avoiding medical jargon and checking understanding when having conversations with patients with learning disabilities.

As a future doctor, I will approach every interaction with an awareness of the systemic pressures that may intensify a patient's distress. Recognising my position of authority, I will strive to reduce power imbalances by encouraging patients to communicate openly and collaboratively. If a patient prefers a different communication style, I will approach the interaction with patience, adaptability, and a proactive effort to understand their needs and preferences.

4) Remember reasonable adjustments

When exploring ways to support patients, I will ensure that reasonable adjustments are a key part of the conversation. Reasonable adjustments are a legal requirement under the Equality Act 2010 (20), aimed at ensuring every individual has equal access to health services. By addressing the challenges related to lack of control in healthcare, reasonable adjustments can significantly improve the experiences of autistic patients with or without learning disabilities. The TEACH acronym (Figure 1)(21), recommended by the Royal College of Physicians, provides a useful tool for supporting patients with autism and learning disabilities.



T = time

Clinical assessments may need more time, which may mean factoring this into working plans, breaking it down into manageable yet effective components, scheduling with carers, or completing assessments outside standard times such as ward rounds.

E = environment

Consider noise, lighting, equipment such as bed height, personal belongings. Would a side room be appropriate?

A = attitude

Consider more open visiting or sharing caring duties in hospital. Consider less frequent monitoring of vital signs or laboratory tests, when the patient is stable.

C = communication

Use communication aids such as pictures, and ensure that communication is non-threatening and non-technical.

H = help

For example, ask for help from a learning disability team.

Figure 1- Royal College of Physicians TEACH tool

This framework guides discussions with patients and their carers about what adjustments might be beneficial. For example, participants in my study frequently expressed the need for quiet waiting areas or longer appointment times, adjustments that align with TEACH principles. Applying this framework has taught me to ask open ended questions, such as, "What can we change to make this more comfortable for you?" and to remain flexible.

By applying frameworks like TEACH, I can better ensure that adjustments are tailored to individual needs, further enhancing communication, building trust, and empowering patients. Together, these strategies create a more inclusive and compassionate healthcare environment for autistic patients with and without learning disabilities.

5) Prepare for each patient

One of the most valuable lessons I learned from the TfA module is that information on how to support patients with learning disabilities is often readily available, if we take the initiative to seek it out and use it effectively. A key starting point is identifying who is involved in the patient's care, such as learning disability nurses or family members. When meeting a patient for the first time, I must approach the interaction with humility, acknowledging that others, especially those who know the patient well, will have deeper insights into their needs. Avoiding assumptions and actively seeking guidance from these individuals is essential, particularly when caring for non-speaking patients with a learning disability.

Once on placement, I encountered a case where the parent of a non-speaking autistic patient explained that their child relied heavily on watching 'Bluey' on their iPad for comfort and focus during stressful situations. This simple insight allowed the care team to ease the patient's distress significantly when taking bloods forming compassionate care. Experiences like this have reinforced the importance of engaging with carers to uncover practical strategies for supporting patients.

Another invaluable resource in caring for patients with learning disabilities is the hospital passport. These documents, often completed by patients or their carers, provide key information such as preferred communication styles, sensory preferences, medical history, and specific coping strategies. They are an essential tool for identifying potential problems and finding effective solutions tailored to the individual. However, hospital passports are often underutilised in clinical practice due to barriers such as a lack of awareness or their being 'buried' within other medical documentation (22). In future practise I will consider this and aim to ensure they are readily accessible within the patient notes and other staff members are aware of it. Overall, by preparing for each patient and gathering as much information as possible I will have a much better chance of providing high quality care.

Conclusion

Reflecting on my experience with Sally, I can see how my understanding of caring for patients with learning disabilities has grown. Initially, I felt guilty for not knowing how to support her, as if my uncertainty represented a failure. Now, I understand that no one can instinctively know every patient's needs. What truly matters is the willingness to learn, adapt, and engage meaningfully.

If I were to care for Sally again, I would approach the interaction with greater confidence and preparation. This preparation would include gathering essential information, such as her hospital passport, to understand her communication and sensory preferences, as well as consulting her learning disability nurse or family for additional insights. These steps would enable me to tailor my care to her unique needs. Directly engaging with Sally would also be central to my approach, using compassionate and clear communication to help Sally feel in control of her healthcare experience. Creating a safe and supportive environment would be my priority, incorporating reasonable adjustments, using the teach TEACH acronym, to ensure she feels empowered and respected. If Sally displayed signs of distress, I would now recognise these behaviours as important forms of communication, prompting a deeper investigation into any underlying physical or emotional causes.

My journey with Sally has reinforced that providing effective care to patients with learning disabilities requires humility, active listening, and a commitment to learning. By embracing these principles, I can not only enhance outcomes for patients with learning disabilities like Sally but also contribute to a more inclusive and empathetic healthcare system for all patients.

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Lived Experience Psychiatry of Intellectual Disability Faculty Group

We are looking for faculty members who also have lived experience of loved ones with intellectual disability, to establish a small working group of psychiatrists with lived experience of intellectual disability outside of their clinical practice, to offer a perspective on Faculty activities.

If you would be interested in potentially joining the group, please contact Samuel Tromans on st386@leicester.ac.uk by 18th July 2025.

Personalised Treatment Packages For Adults With Learning Disabilities Who Display Aggression in Community Settings (PETAL)

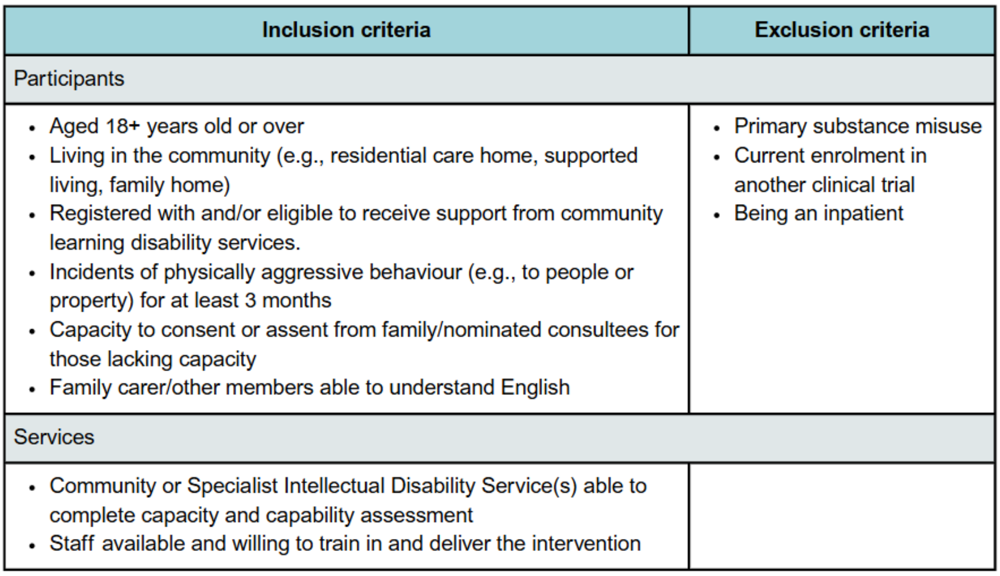
The PETAL trial is a national cluster randomised controlled trial testing the effectiveness of the PETAL therapy.

We are looking for community learning disability services or specialist learning disability services that are interested in joining the PETAL trial.

The aim of PETAL therapy is to support people with learning disabilities and their carers to reduce aggressive challenging behaviour and improve their lives. It is a personalised treatment package that consists of seven modules and two review sessions delivered in up to 14 weeks. PETAL therapy is delivered by trained therapists who are Band 4 or above healthcare professionals.

We are looking for teams that can join the trial to be randomised and attend therapist training sessions in either July, September or November.

If you and your team are interested in joining the PETAL trial, please contact our trial manager Rebecca Griffiths rebecca.griffiths@ucl.ac.uk



Inclusion criteria	Exclusion criteria
Participants	
• Aged 18+ years old or over • Living in the community (e.g., residential care home, supported living, family home) • Registered with and/or eligible to receive support from community learning disability services. • Incidents of physically aggressive behaviour (e.g., to people or property) for at least 3 months • Capacity to consent or assent from family/nominated consultees for those lacking capacity • Family carer/other members able to understand English	• Primary substance misuse • Current enrolment in another clinical trial • Being an inpatient
Services	
• Community or Specialist Intellectual Disability Service(s) able to complete capacity and capability assessment • Staff available and willing to train in and deliver the intervention	

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Joan Bicknell Medical Student Essay Prize:

Deadline: 1 December 2025

Prize: £250 and subsidised attendance at the faculty conference

Eligible: medical students in the UK

Educational bursary:

An educational bursary fund is available for resident doctors and SAS doctors working in the field of intellectual disability who can't find funding to attend College meetings and other appropriate educational activities.

Deadline: available throughout the year

Bursary: up to £200

Eligible: UK resident doctors and SAS doctors

Gregory O'Brien Travelling Fellowship:

Deadline: 31 December 2025 (awarded biannually)

Prize: £1,000

Eligible: Applicants must be resident doctors (core or higher training) in an approved UK training scheme, or be within the first three years of a consultant post to enter.

Explore the range of prizes and bursaries offered by the RCPsych Intellectual Disability Faculty:

Intellectual disability faculty prizes and bursaries

UPCOMING FACULTY CONFERENCE

Autumn Faculty Conference will be held at Voco Hotel in Leicester on Tuesday 7th to Wednesday 8th October. Further details, including the full programme and a booking link: Faculty of the Psychiatry of Intellectual Disability Conference 2025

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

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