

Psychiatry of Intellectual Disability

May 2023 Vol 24, Issue 1



Newsletter of the Intellectual
Disability Psychiatry Faculty



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Disclaimer: The views expressed in this publication are the personal views of the authors and do not necessarily reflect the College's position.

Editorial

Dr Sonya Rudra

Lead Editor for Spring 2023 ID Faculty Newsletter

We are so pleased to welcome you to the Spring 2023 Edition of the Intellectual Disability (ID) Psychiatry Faculty Newsletter. As with many projects, the newsletter took a brief hiatus during the COVID-19 pandemic. We have convened a new editorial committee and are pleased to be back on your screens after more than 18 months.

We start the newsletter with an interview with Dr Inder Sawhney, the ID Faculty Chair. Since her election to Chair of ID Faculty in 2022, Dr Inder Sawhney has been a huge influence in reigniting this newsletter. We are incredibly grateful for her time and support. As you read about her journey, see if you can spot Monty, her 4-legged bestie and stressbuster.

There are further updates and insights from the ID Faculty Executive Committee. Dr Mary Barrett gives her final update as she comes to end of her term as SAC Chair - We thank you, Mary, for everything you have done to support education and training in the ID Faculty. I also come to the end of my term as Higher Trainee Rep and give a final update reflecting on the year gone by. Dr Niraj Singh invites you to think about Climate Change and to consider joining the ID sustainability working group. You can also find a link to the ID Faculty's [latest recruitment video](#) at the end of my article on "A Career in ID Psychiatry".

There is a range of further articles to suit all interests. The topical articles are thought-provoking pieces of writing, whilst the sharing of local initiatives showcase the fantastic work going on across the country. We hope these may drive some ideas for your own services.

Dr Shahib writes a compelling reflection on her personal journey in "Lost in Translation" and Dr Bakhiet takes us on an eye-opening trip into Sudan. You can also read about the experience of Jesmine Dhooper, Nottingham University medical student on her ID placement, calling for all medical students to seek placements in ID.

For those of you who missed it, Dr Gillian Brown gives an overview on the first Joint Forensic and Intellectual Disability Psychiatry Conference. Remember, if you are attending any upcoming conferences do send us your "Conference Watch" articles.

We received an overwhelming number of articles for this issue. We were so impressed by the range of submissions and send a huge thank you to all of our contributors. There are so many talented writers working in ID and we encourage you to keep submitting articles, consider reaching out to join the editorial committee and engage with the prizes/bursaries offered by the ID Faculty. Further details of all these are on [page 36](#) including our 2022 prize winners – Congratulations to all of you!

Finally, thank you to the [Editorial Committee](#) and Kittie Kottasz without whom this newsletter would not be possible.

We hope you will all enjoy reading through these articles as much as we have. Please continue to send any queries, submissions or expressions of interest to newsletter.psychid@gmail.com.

Interview with the ID Faculty Chair – Dr Inder Sawhney

Interview by Dr Maruf Mustapha, ST4 ID psychiatry



Who is Dr Inder Sawhney, the ID psychiatrist?

My journey started in India, where I was born and brought up. My father was in the army, and that involved frequent movement across the entire country; hence I attended many different schools. Although there was not much continuity, this presented me with an invaluable opportunity to meet and make friends from different backgrounds and learn about other cultures. This left me with an aptitude from an early age of seeing things from different perspectives and having a flexible approach to thinking and problem-solving. Moreover, this experience equipped me to become adept at adapting to new /unique situations.

Because I attended medical school in India, my degree could not be recognised in the UK until I cleared the licensing exam (PLAB). Hence, my first job was as a shop assistant to support myself. Shortly afterwards, I started working as an admin in a GP surgery; the flexible working hours allowed me to study until I cleared the PLAB. There was immense pressure, responsibility of a young son and no friends or family here for additional support; hence clearing the exams in the first go was a top priority, which I succeeded at.

I got my first job as a doctor in the UK in beautiful Wales. I remained committed and maintained the high level of focus and drive which I started my medical journey in the UK with, and this helped me scale through the MRCPsych exams. My parents came from India to support me while preparing for the

exams. They have been huge pillars of support and instrumental in my success.

After that, I started higher training in Oxford. As part of my education, I also completed a master's degree in law. My first Consultant job was in 2007 in Essex. Soon after becoming a consultant, I was appointed as the medical lead and then clinical director.

You've had a very distinguished career so far. What professional achievements are your highlights?

It was personally gratifying to be a finalist for Clinical Leader of the Year in the prestigious HSJ awards and being named as one of the top 3 psychiatrists of the year by the Royal College of Psychiatrists last year. For me, it was a recognition of catering to the unique needs of our vulnerable patient group and ensuring their health needs remain at the forefront and in focus. It was also an acknowledgement of our colleagues' sterling work in putting our speciality on the map at the national level; raising awareness of the critical role that intellectual disability psychiatry services play in our healthcare system; and changing the perception of ID services both within psychiatry, amongst our other medical colleagues and the wider public. This award serves as a reminder of the positive impact that our work can have, and we must continue to strive towards achieving excellence in our field to ensure that our patients receive the best possible care.

What are the challenges for clinicians in ID psychiatry?

The biggest challenge so far is how the needs of people living with intellectual disabilities, who are among the most marginalised in our society, are fully recognised and given the level of care and attention they deserve. The voices of our patients often get lost and as clinicians we need to ensure they are amplified and get heard; we have to, as part of our service roles, be advocates and champions for many of their needs, at the same time not taking away agency and autonomy where it exists. So, this is no doubt a delicate balancing act..

We also have to interface with our colleagues in acute medicine, primary care, social care, education and many other decision-making spaces and fora in health and social care to encourage not equal but equitable access and attention to the unique needs of people living with intellectual disabilities.

What are your thoughts about overcoming the challenges on recruitment?

Recruitment and retention of psychiatrists into the fold of intellectual disability psychiatry is a critical priority.

I want ID psychiatry to be seen as a vibrant and dynamic subspecialty of psychiatry, which encapsulates the biopsychosocial approach to problem-solving in psychiatry, portrays the themes of multidisciplinary working, advocacy, ethical client-centred decision-making, and attracts vibrant, passionate and committed people. Specific approaches to achieving this would include but are not limited to: Improving access to research and quality improvement tools; raising the profile of psychiatry amongst medical students; for trainees to have a well-rounded training experience; and for further development of forensic ID as part of the offer in training. We have worked hard to achieve

some modest gains in the training program, by improving competencies of supervisors and trainees in epilepsy, genetics, forensic, medicolegal issues, and dementia, and we hope to keep the momentum of improvement going. It is about building respect for our specialty so that it is no longer viewed as a Cinderella service.

You have previously mentioned how one of the priorities in intellectual disability psychiatry is research. Please tell us a bit more about this. What are the issues hampering research output, and what is your vision for building research capacity in intellectual disability psychiatry?

Yes, that is a pertinent point. Research is one of the key priorities of the Faculty. However, within the Faculty, we acknowledge that we aren't where we want to be in academic ID psychiatry. We are lagging, and this is due to several reasons, some of which include the dwindling human capacity/resource in academic psychiatry in general.

We can all contribute by engaging in academic activities at different levels. Jobbing Psychiatrists can support roles in teaching and education by taking on the role of clinical supervisors or examiners. We encourage our clinical colleagues to support academic/research colleagues by helping recruitment for research studies.

There are also plans to develop a repository of planned or ongoing research work accessible online for aspiring clinicians to look into and liaise with the principal investigators as listed. The objective is to build collaborative work in our speciality across the academic world. Improving access to information like this would go a long way in meeting the expected research and quality improvement expectations, output, and standards.

Thank you so much. Any final thoughts or advice that you can share to aspiring leaders from the challenges you have faced on your own personal journey?

Being a female BAME leader can present unique challenges. It is not uncommon for colleagues who share similar characteristics to face workplace bullying and discrimination. Sometimes it is acts of subtle undermining; other times, the writing is clearly on the wall, but one needs to muster the courage and be bold and brave enough to call it out. A piece of advice and the mantra to follow "Keep calm and stand up". You owe this to yourself. It is important for us as clinical leaders to promote diversity and inclusivity in in our workplace and ensure colleagues feel empowered to speak up. I end on the poem of the nobel Laureate Tagore, "where the mind is without fear and the head is held high.." something we need to aspire to create!

Thank you so much Dr Inder Sawhney.



Dr Indermeet Sawhney with Monty- her 4-legged bestie and stressbuster.

View from the ID Specialty Advisory Committee

Dr Mary Barrett

Consultant Psychiatrist for Adults with Learning Disabilities

East Midlands Region Training Programme Director

Chair, Intellectual Disability Specialty Advisory Committee



I am pleased to have this opportunity to update the Faculty on education and training matters, as a lot has happened since the last newsletter was published, and more will continue to happen over the coming months.

Curriculum update

Most of our trainees are now using the new 2022 Curriculum and accompanying Portfolio. This change has had a considerable impact for both trainees and trainers, not to mention TPDs and ARCP Panels! The main reported challenge has been getting to grips with the new Placement-Specific Personal Development Plan (PSPDP). Please can I urge everyone who has not already done so to look at the [Curriculum Hub](#) and complete the [e-learning package](#) found here. This has been specifically designed to take you through everything you need to know.

The SAC has now finished working on a range of supporting resources to help with Curriculum implementation. This is in [the Documents and Resources](#) section of the Curriculum Hub. Here you will find our latest additions – a Dual ID/CAP PDP and our Library of Activities – we have been the front-runner in getting such resources completed and approved by the RCPsych and have already received positive feedback from those accessing them.

ID Forensic Dual Training

Further to meeting with the GMC, we are now pulling together the evidence needed for our Dual Training application. Scoping has found significant differences in Forensic-ID placement opportunities across the four nations (and within them), which will need

consideration when we look at deliverability. As part of the consultation process, I am due to attend the forthcoming Heads of School Meeting to discuss our proposal and seek their advice and support.

Run-through Training

It was pleasing to have some of our first cohort of run-through trainees attend the 2022 Annual ID Faculty Meeting, an experience they really benefitted from. Support meetings have now been held with both trainee and mentor cohorts and further to the latter we have drafted guidance on the role of the mentor. There will be an opportunity for mentors and mentees to meet – this time in person – at Congress later this year, which we are really looking forward to.

A further round of run-through posts will be offered through HEE for the August 2023 intake; we await confirmation of numbers and locations. So far this has been a Health Education England initiative, however I am aware that other nations are also now considering setting up similar run-through programmes.

Work with the Academy of Medical Royal Colleges

Work has restarted on developing shared learning on neurodevelopmental disorders, now badged as 'CPD for all'. Dr Raja Mukherjee has led on developing the Autism/associated conditions document and I have led on the ID document. These have been approved in principle by the Academy Professional Development Committee and are now being taken to the GMC for their review.

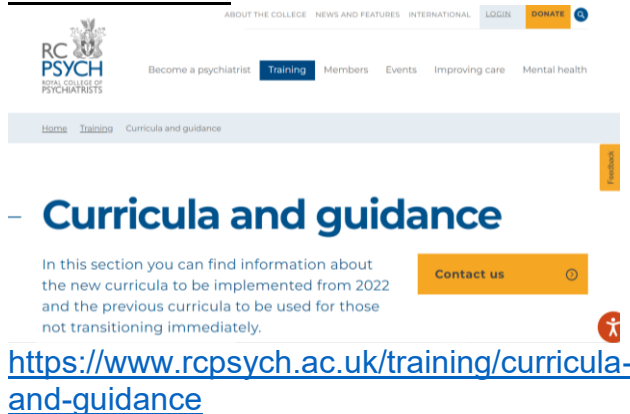
Role of the SAC

Now that the curriculum implementation has been achieved, the role of the SAC – and its membership - is due for change. I will be reaching the end of my term in the first half of 2023, so a new Chair will be appointed, along with many current members demitting and new ones joining. I am hoping to encourage some of the current TPDs to join the committee, alongside the trainee reps, to take our educational governance forward; in addition, there may be the opportunity for others with a particular interest in education and training to join. This will clearly be a time of major change for the SAC.

Given that is the case, this will be my last newsletter report as SAC Chair. Can I thank all the members of the SAC who have worked with me over the last few years to support education and training in our Faculty.

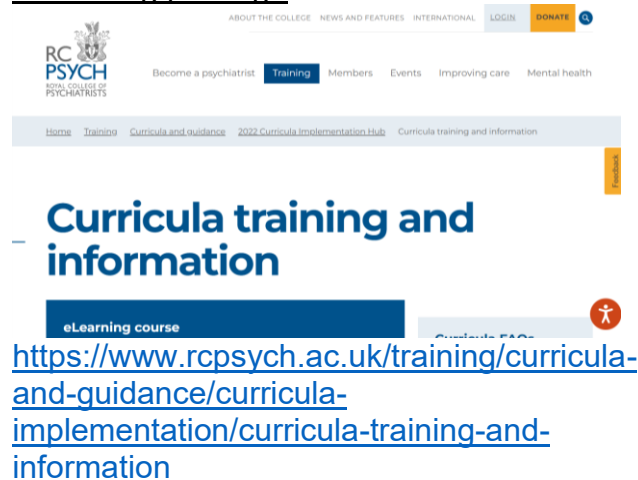
Links to resources:

Curriculum Hub:



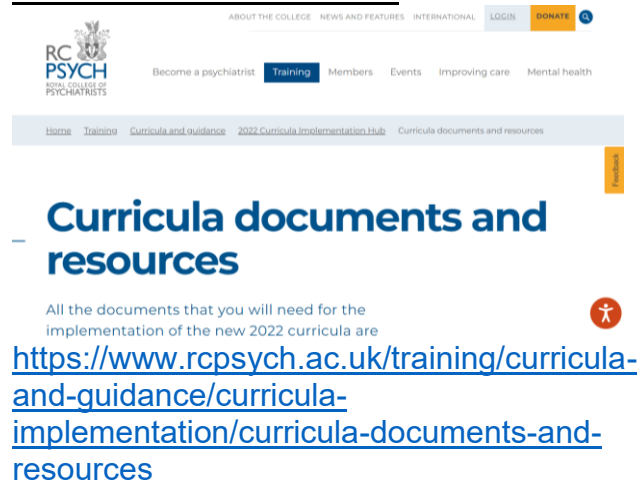
<https://www.rcpsych.ac.uk/training/curricula-and-guidance>

E-learning package:



<https://www.rcpsych.ac.uk/training/curricula-and-guidance/curricula-implementation/curricula-training-and-information>

Documents and Resources:



<https://www.rcpsych.ac.uk/training/curricula-and-guidance/curricula-implementation/curricula-documents-and-resources>

View from the National Trainee Reps – Reflections on the year gone by..

Dr Sonya Rudra, ST6 Intellectual Disability

Dr Mrityun-Jai Kumar, ST5 CAMHS-ID



It has been an interesting and eventful year hallmarked by the experience of dealing with many unknowns like vagaries of the pandemic and working in hybrid modes. It is hard to recollect any other year in recent history which has shaped the course of our practise by such a magnitude! We have however thrived through, and become much more IT savvy if not wiser!

Dr Sonya Rudra took over the ID Faculty ST Representative role in May 2022 and Dr Jai Kumar stepped into the role in September 2022 following previous ST Representative Dr Abigail Swift's long term leave. Can we begin by saying that it has been a privilege to represent you through this period and an absolute delight to get to know you all.

This year started with the implementation of the new and revised GMC Curriculum. Like most new endeavours this had some teething issues but with support of the College and Faculty most, if not all of us, are now familiar with the new changes. We have supported the SAC in putting together a Library of Activities for mapping to the curriculum. It was widely acknowledged that while in principle the curriculum changes were welcome, there were some challenges in translating it to the e-portfolio. Follow up discussions in regional representative meetings suggested that peer support networks have been particularly useful in addressing these issues, which has been a great initiative led by trainees.

The Specialist Advisory Committee is now supporting with collating a list of ID inpatient placements for trainees to access for those interested in organising taster days and special interest sessions. We heard your feedback that inpatient experience was

lacking and this is now a work in progress. Rest assured the Faculty is listening!

Abigail and Sonya have created an inventory of resources across intellectual disability psychiatry which went live on the Royal College of Psychiatrists website in August 2022. This is aimed at both students and trainees and has received positive feedback. Suggestions for additional resources to be added are very welcome. The learning resources can be found here: <https://www.rcpsych.ac.uk/members/your-faculties/intellectual-disability-psychiatry/training-resources>

This year has also seen the introduction of ID run-through trainees which promises to promote retention and recruitment in the speciality. Currently, while the numbers are small, trainees are paired with a local Specialist Trainee Mentor for support. We as national reps are involved in the process of engaging them proactively and feeding back to ID executive.

We are keen to promote the engagement of Specialist Trainees with the College's ID Faculty. We are delighted that we have been able to facilitate Specialist Trainees engagement in Epilepsy and Neurodevelopment Disorder subgroups. Whilst Sonya has taken proactive role in recruitment committees, Jai has been active in supporting with the College's outcome framework for Faculty of ID reports. Sonya is also working with the Academic group to run focus groups with higher trainees about their experiences of academia. It is not too late to get involved with the Faculty so get in touch!

This is also an interesting time as changes are afoot with the Medical Education Reform Program (MERP), a nationwide program to

address inequalities in higher trainee numbers. In the first phase of program (2023-25) both ID and CAMHS national training numbers would be redistributed to areas of geographical need. While the exact clarity in numbers both for dual (ID-CAMHS) training as well as ID training numbers are currently in consideration; the ID Faculty and we, as your representatives, are actively feeding back issues. We are consciously aware of recruitment challenges in some of the areas, they have been fed back to MERP team. We will keep you updated about the progress.

Conferences and events: In the past year, we had regular meetings, and conferences. Following the election of Dr Sawhney as chair of the ID Faculty Executive in June 2022, the tradition of regular meetings with higher trainees across the four nations has continued with virtual platforms facilitating good attendance. The outreach and direct communication with Higher Trainees has been invaluable in establishing a close knit forum for communications.

A National Trainees conference was organised in November 2022 by the London Region, which was very well attended by trainees across the country. The conference was as much stimulating intellectually as indeed inclusive, followed by a networking social evening. Scotland have taken on the responsibility of hosting the National ID Trainees Conference for 2023. We look forward to what they have in store for us!

It was also encouraging to see great participation from both Specialist and Run-through trainees at the ID Annual Conference. It was great to see posters and presentations by trainees as part of the Alec Shapiro Award. We were able to use this opportunity to network with trainees across the four nations and evolve synergy and promote coherence in our discipline. This was followed

by more trainee input at the Spring Conference 2023.

As part of the remit of our role as your representatives, we have endeavoured to be active on social media, on twitter, basecamp and national WhatsApp groups. Whilst we have good interactions and feedback, we think there is a need to be more proactive in showcasing and sharing what a wonderful bunch we are! This newsletter is a start in allowing us to do just that!

You can find information about upcoming newsletter issues here: <https://www.rcpsych.ac.uk/members/your-faculties/intellectual-disability-psychiatry/news-and-resources>

For those interested in joining the Editorial Team please do email newsletter.psychid@gmail.com.

Finally, Sonya finished her term as ID Rep in May 2023 and handed over to Dr David Anderson, ST5 from North East. Many congratulations and welcome to the new role, David! We have no doubt you will have a wonderful experience working with your fellow trainees and the ID Executive Committee.

Climate Change – What can psychiatrists do about it?

Dr Niraj Singh, Consultant ID Psychiatrist

ID Faculty Sustainability Chair



Across the world, climate change and the destruction of the environment, are resulting in significant impacts on individuals, as well as a loss of biodiversity. We have witnessed, across the world, increased climate disasters from floods, severe storms, and droughts. The UK also has experienced high temperatures as well as increased flooding and as such is not immune in spite of climate change impacting the global south disproportionately. (RCPsych, 2021)

Pollution and biodiversity loss have created a health crisis. When we think of climate change we have to think of planetary health. In fact, many have used the term climate change as a lighter term for the current planetary disruption underway. As well as the potential physical health impact, climate change can exacerbate pre-existing mental health problems and increase the incidence of mental illness, including anxiety, depression, post-traumatic stress, as well as the relapse of affective disorders and psychotic illness.

Carbon emissions are usually used as the main measure and are a major contributor to climate change. CO₂ accounts for about 76% of total greenhouse gas emission, methane primarily from agriculture contributes 16% and nitrous oxide agriculture contributes 6%. The agricultural industry is a major contributor. However, in terms of carbon the NHS is a major contributor according to NHS England 2020, it accounts for between 4 - 5% of the total.

The figure below shows the approximate breakdown of carbon emissions within the NHS (Tennison et al, 2021). You'll note that the vast majority is related to medicines, medical equipment, and other supply chain.

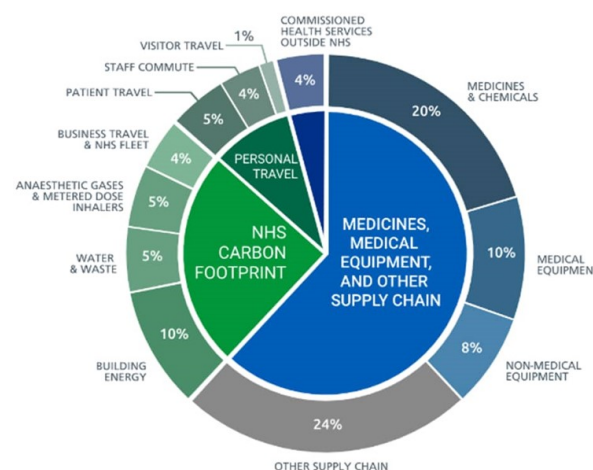


Figure 1: The approximate breakdown of carbon emissions within the NHS

Therefore, clinicians have a key role in being part of the solution. This can be done in the following ways'

1. Promoting prevention, detection and early treatment of illness.
2. Supporting patients to embed important lifestyle changes early on; Emphasis on taking care of physical health and smoking cessation.
3. Empowering patients; support co-production period indication and carer support.

4. Social prescribing; The integration of social prescribing in nature-based care is vital and whilst the main view is for primary care, social prescribing should be embedded into community and into patient mental health care.
5. Keeping tabs on one's own carbon footprint and leading by example; Remote working has resulted in a drop in many people's carbon footprint, however the use of single use plastics continues. Consider GREEN environmental modifications if you are at home, and the appropriate recycling of materials

As clinicians and particularly for those working in intellectual disability, in-line with STOMP and good medical practice, appropriate indications for prescribing need to be proportionate and necessary. Over recent years we have looked at prescribing from the lens of STOMP, however, it is also vital that we consider the climate impact of medicines. Therefore, ensuring we are prescribing using the lowest effective dose for the shortest period, whilst monitoring response and side effects, will continue to be vital. Embedding support with the wider MDT, including psychological approaches is also important. This no doubt does become more difficult when resources are strained and recruitment is a challenge. It is important to be mindful that psychotropics can be excreted in wastewater and also be hazardous to the environment.

The table shows the projection reduction in economic and environmental costs that could be achieved by increasing the interval of a depot injection to a maximum of 4 weeks and reducing dose to the maximum effective dose. This will result in a carbon footprint saving of 68kg per annum (*Maughan et al, 2021*), which is the equivalent of driving 1000 miles in a petrol vehicle. Therefore, as prescribers we have a significant role to play.

Table 4 Projected reductions in economic and environmental costs that could be achieved by increasing interval of injection to maximum 4 weeks and reducing dose to maximal effective dose

Resource	Potential financial savings, £/year		Potential carbon footprint savings, kg CO ₂ e/year	
	For each patient	Nationally	For each patient	For England
Medication	22	152 935	10	65 762
Needle and syringe	3	1631	1	110
Appointment	202	128 250	138	87 750
Travel	23	14 310	20	12 623
Total	250	297 126	169	166 245

Table 1: The projected reduction in economic and environmental costs that could be achieved by increasing the interval of a depot injection to a maximum of 4 weeks and reducing dose to the maximum effective dose.

Sustainable healthcare delivers high quality care without damaging the environment. It is good value for money and delivers a positive social impact. Every one of us has a responsibility for this and can contribute. In future articles I will discuss case examples.

If anyone would like to join the ID sustainability working group please contact me on nirajsingh1@nhs.net

References

Royal College of Psychiatrists (2021) Position Statement PS03/21: Our planet's climate and ecological emergency. Available at [position-statement-ps03-21-climate-and-ecological-emergencies-2021.pdf](https://www.rcpsych.ac.uk/position-statements/ps03-21-climate-and-ecological-emergencies-2021.pdf) (rcpsych.ac.uk)

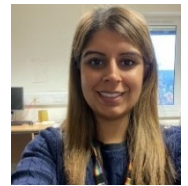
Tennison, I., Roschnik, S., Ashby, B., Boyd, R., Hamilton, I., Oreszczyn, T., Owen, A., Romanello, M., Ruyssevelt, P., Sherman, J.D., Smith, A.Z.P., Steele, K., Watts, N., Eckelman, M.J., 2021. Health care's response to climate change: a carbon footprint assessment of the NHS in England. *The Lancet Planetary Health* 5, e84–e92

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A Career in ID Psychiatry

Dr Sonya Rudra, ST6 in ID Psychiatry

Member, ID Exec Recruitment Working Group



Psychiatrists in intellectual disability specialise in the *recognition, diagnosis* and *management* of mental health problems in people with intellectual disabilities. But that is really just the start!

Although precise estimates vary, people with an intellectual disability have higher rates of many types of mental illness compared to the general population. However, mental illness (as well as physical) can present very differently in those with an intellectual disability. Therefore, as a psychiatrist you may be less likely to see “typical symptoms of depression”, “overt psychotic symptoms” or “well-formed delusions” etc. Often, an illness may present only with a change in behaviour and the patient may have limited communication to express their needs. It takes *holistic thinking* and *creative assessment techniques* to establish rapport and determine whether there is a mental illness or other reason for this change from a person’s baseline. For many this specialty is *detective-work*!

Sadly, “science” has not always served people with intellectual disabilities well. From being subjects of cruel experimentation, derogatory language and locked away in institutions, often they were prescribed high doses of sedating medication. Since the 1980s there has been a significant shift in attitudes towards people with learning disabilities and a huge drive to support people to live fulfilled lives in the community. Nowadays, we acknowledge the risks of overprescribing medications in both the short-term and long-term, particularly when there is no clear indication for them. As psychiatrists in intellectual disability we are *advocates* for this group and support Stopping Over Medication of People with Intellectual

Disability and/or Autism (NHS England, 2019).

In moving away from a purely medical model of working, this specialty has formed a strong culture of *multi-disciplinary team working* with professionals including Psychologists, Speech and Language Therapists, Nurse Occupational Therapists all working towards the same goal. You also work with external agencies including schools, social care and residential homes. This collaboration ensures that all patients and their families receive the best possible care.

The patient group is so *diverse*, with higher rates of other neurodevelopmental conditions such as attention deficit hyperactivity disorder (ADHD) and autism spectrum disorder (ASD); higher rates of physical conditions such as epilepsy; and higher rates of rare genetic conditions. You will continue to see older adults and require an up-to-date knowledge of relevant law. The complexity keeps every day *interesting*, and you may find yourself becoming an *expert* in more areas than one.

It goes without saying, working in this field requires patience, empathy and dedication. It is therefore not surprising that you meet the most *inspiring* patients, carers, family members and staff. People with an intellectual disability are amongst the most vulnerable groups in society and those who work in this field are passionate about improving their quality of lives and health outcomes. Every day is a chance to *make a real difference*!

For those who are interested in research, opportunities in this field are vast. There has been a dearth of high-quality early research for reasons including ethical dilemmas, poor

access, dependence on staff, a difficult consent procedure, the lack of validated tools and the burden of behaviours that challenge. As we move forward, research is both required and encouraged. There is an international network of enthusiastic intellectual disability psychiatrists keen to promote and *support academics* in this field. As well as research, *opportunities* for involvement in leadership roles, service development and teaching are plentiful.

The jobs in this specialty vary from inpatient, community-based, forensic-settings, liaison and LD-CAMHS (with other dual training posts and jobs to come). Even within these roles your days will always be *varied*. So, if you are looking for a *fascinating, rewarding* and truly *patient-centred* career, then ID psychiatry could be for you.

Link to Dr Sonya Rudra's talk at Royal College of Psychiatrists London Divisions Discover Psychiatry Event 2022 for medical students: "A career in Intellectual Disability Psychiatry": <https://youtu.be/JdC1OOj9Vm4>

Reference

NHS England. (2019). Stopping over medication of people with a learning disability, autism or both (STOMP). NHS. Retrieved 23 November from <https://www.england.nhs.uk/learning-disabilities/improving-health/stomp/>

Link to ID Faculty Recruitment Steering Group video:



<https://vimeo.com/821238201/94c9417e70?share=copy>

Artificial Intelligence and ADHD Assessment – Risks and Opportunities

Dr Douglas Kohler, ST4 Higher Psychiatric Trainee (CAMHS/LD)

Dr Mathanki Krishnamoorthy, CT2 trainee

Buckinghamshire Community Learning Disability Team

Referrals for the assessment of attention deficit hyperactivity disorder (ADHD) in adults have greatly increased across the UK in recent years, and in some areas waiting times of between two and five years for an NHS assessment have been reported. Whilst some patients may have the means to access diagnosis and treatment in the private sector, this poses a financial burden which may prove insurmountable for many, especially those from disadvantaged backgrounds. The reasons for the bottlenecking of diagnostic pathways in the NHS are complex, and with no easy solutions in sight, there has been a great interest in methods of streamlining the diagnostic process.

Much research has been directed at developing computerised tools to aid the assessment of ADHD. One notable example is QbTest, recently the subject of a National Institute for Health and Clinical Excellence (NICE) innovation briefing, which involves a combination of a continuous-performance test and motion-tracking apparatus designed to assess concentration, movement, and impulsivity. Presently in use across 65 NHS Trusts, the evidence analysed by NICE suggests that QbTest may reduce the clinician time required for the assessment of ADHD by 20% to 30%, without a significant loss of diagnostic accuracy (NICE, 2023).

These kinds of tests are likely only the beginning: the clinical use of artificial intelligence (AI) – a blanket term describing multiple methods of information synthesis and automated decision-making – is on the rise. These tools vary from algorithms which recognise and classify patterns such as subtle differences in radiology images, to

“conversational” AIs which interpret natural language inputs and respond in kind, such as the Generative Pre-trained Transformer (GPT) model and its ChatGPT implementation. One prominent example is Limbic Access, now in routine use by several Improving Access to Psychological Therapies (IAPT) services in the UK. This software presents a chat interface as a self-referral portal, collecting data from patients prior to their first contact with a clinician, and claims to have produced an increase in recovery rates which is both clinically significant and cost-efficient (Rollwage et al, 2022).

Perhaps similar approaches could be useful in the assessment of ADHD. Tachmazidis et al. (2021) recently developed an AI prediction model that integrated data from Connors Adult ADHD Rating Scale, QbTest, patient demographics, and the Diagnostic Interview for ADHD in Adults (DIVA); their model claimed an 85% diagnostic accuracy rate when used alone, rising to 95% when used as a decision-support tool. A significant benefit of the latter use was that the tool could accurately classify cases which clearly did or did not meet diagnostic criteria, whilst flagging complex and borderline cases for expert oversight.

There are however reasons to be cautious of computerised assessments and clinical AI. NICE found that most families felt QbTest did not help them understand why diagnostic decisions were being made (NICE, 2023), and as the sophistication and autonomy of clinical AI increases, we should expect that AI decisions will become increasingly opaque to patients, clinicians, and the public. Wu et al. (2023) noted that AIs can produce predictions which they are unable to explain, which can be a major barrier to their wider acceptance and implementation. This is particularly

problematic in the case of proprietary software such as Limbic Access, the workings of which cannot be easily examined from the outside. This opacity has two main dangers: it may encourage risky overreliance on the judgement of software which may not be well-founded and which cannot be subjected to meaningful scrutiny; and may erode confidence in clinical judgements that are backed by these tools, and in the systems which use them.

More sophisticated tools such as GPT also carry their own risks, particularly around unexpected emergent behaviours. Our own informal experiments with ChatGPT proved revealing in this regard: ChatGPT's terms of use prohibit its use for providing medical advice (Open AI, 2023), and the software has inbuilt safeguards designed to make it refuse to provide such information; nonetheless, we were able to "jailbreak" ChatGPT remarkably easily and convince it to suggest potential treatment options for ADHD. Whilst its suggestions were relatively innocuous – a combination of organisational advice and mindfulness that some patients could find helpful – it is nonetheless concerning that the software could be made to respond in this fashion.

It seems likely that the clinical use of AI is only going to increase in coming years. Such innovations should, we feel, be viewed with a degree of optimism for the potential that they may have in enhancing clinical care. It would however be prudent to maintain a degree of scepticism and caution around their use – especially when their workings are not made clear – and it is vitally important to ensure that there is adequate oversight of the use of clinical AI, both at a regulatory level and a clinical one. Like any tool, AI should not replace clinical expertise, but supplement it.

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Identity and Intellectual Disability: an Introduction

Dr Mrityun-Jai Kumar, ST5 in CAMHS-ID



Identity is a relatively commonly used term which remains difficult to define. Identity refers to the set of characteristics and traits that define an individual or group and differentiate them from others. Although the concept of self and identity are considered complementary to each other, leading identity researchers like Deaux (1993) define Identity by contrasting it with 'sense of self' and considering it more linked to various social roles.

Identity is not fixed or innate but rather, it is an ongoing and dynamic process that is shaped by individual experiences and interactions with others. Sociologists often distinguish between individual identity and social identity. Individual identity refers to an individual's sense of self, whilst social identity refers to an individual's sense of belonging to a particular social group. Tajfel defined social identity as *"that part of an individual's self-concept which derives from his knowledge of his membership of a social group (or groups), together with the value and emotional significance attached to that membership"* (Tajfel and Turner, 2001).

Sociological perspectives on identity emphasize that identity is not just an individual phenomenon but is deeply rooted in social structures and relationships. Individuals are not passive recipients of identity but actively participate in constructing and negotiating their identities in response to social contexts and interactions with others. Thus, identity is seen as a social product that is shaped by social processes and relations.

Tajfel's assumption hence becomes an important perspective in the understanding of disability identity as it implies that by having a disabled social identity, group membership becomes sufficient to cause prejudice. It also

places an emphasis on internal self-esteem as a group as a key process.

The central premise in the current article is to examine introductory theoretical concepts in intellectual disabled identity and current evidence in this area.

Ideas of self

Whilst the psychological theory has evolved with individual centred ideas of 'sense of self' among the social theorists Mead believed that individuals develop a sense of self through social interactions with others. He argued that the self is not something that individuals possess inherently, but rather, it is something that is constructed through social processes and interactions. According to Mead, the sense of self is composed of two elements: the "I" and the "me." The development of disability theory approaches have allowed a more emancipating approach to disability in general but somehow intellectual disability has been left at the margins.

Intellectual Disability and Identity

The identity of people with intellectual disabilities (ID) is a complex and multifaceted issue and sociological perspectives offer valuable insights into how people with learning disabilities are perceived and constructed within society.

Beart, Hardy and Buchan (2005) examined how people with intellectual disabilities viewed their social identity and has reported that evidence suggests that many people with intellectual disabilities do not view their social identity as applicable to them, and that they experience the stigma attached to this identity through their interactions with others. This review focuses on studies that have sought to

understand how people who are categorized as having intellectual disabilities *think and feel* about their identity.

Finlay and Lyons (1998) working with people with mild-to-moderate intellectual disabilities to explore the relationship between the view of the identity of intellectual disabilities, and their own self-concept, report that group identification was not correlated with group evaluation, in terms of their measures of self-esteem. Thus, group identification did not make them feel worse about themselves. Those who evaluated the group negatively, did not feel worse about themselves and those who admitted the label did not evaluate it more positively than those who denied the label.

The two reviews show that people with intellectual disabilities do not appear to see this identity as applicable to them even if significant others do (Jahoda, Markova and Cattermole, 1988), and when they do it has no bearing on their self-esteem (Finlay and Lyons, 1998). While commenting in another ethnographic review, Jahoda *et al.* (2010) examines this further and writes '*This did not mean that they denied their disabilities or the particular difficulties arising from their impairments, but they refused to accept the negative stereotype of a disabled person such as being regarded as incapable of making choices in their lives*'. This opens up a new possibility of looking at their social identity from a perspective of resilience pathways, and perhaps to examine pathways further in the way they project their identity to others.

Examining the intellectual disabilities construction of social identity, Logeswaran *et al.* (2019) reviewed how people with intellectual disabilities view their "label". Most studies showed that people with ID were aware of their intellectual disability label and their membership of this stigmatized category, but it was not thought to be an important aspect of their identity.

The label of "intellectual disability" continues to be a dominant and stigmatizing one, this reflects in seminal works in the area like Edgerton., (1993) who have

acknowledged the impact of stigma on ID identity. Overall the Logeswaran concludes that people with ID generally appear aware of the label ascribed to them, whilst some distance themselves from the label or reject it altogether. Having an intellectual disability mostly appears not to be a dominant feature of their identity, it may be in others' eyes and this is the most widely researched.

This indicates the need for future research to explore the role of group identification, social support and peer support in making people with intellectual disabilities more resilient to the negative consequences of stigma.

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Learning Across Psychiatry Specialties: Biological and Psychological Symptoms of Dementia and Behaviour that Challenges of Intellectual Disability

Dr Sara Moghrabi, CT2 Psychiatry Trainee



I am a psychiatry core trainee working within a Community Intellectual Disability Mental Health Team at present. I had just finished a placement in a Community Older Adult Mental Health Team before starting my current post. I have noted some similarities between Biological and Psychological Symptoms of Dementia (BPSD) and Behaviour that Challenges of Intellectual Disability which piqued my interest to try and explore with the aim of sharing the knowledge and learning across both disciplines, thereby optimising treatment and care for patients under both teams. In this article, I reflect on some overlapping points between both presentations and briefly highlight the basic non-pharmacological approach models for them.

BPSD and Behaviour that Challenges of Intellectual Disability have a few meeting points where the presentation and approaches to management are quite similar albeit the original conditions are not. Intellectual Disability is defined by impaired cognitive functioning and adaptive behaviours occurring in the developmental period. Dementia refers to a chronic or progressive disorder which results in the deterioration of cognitive function beyond the usual consequences of biological aging. These impairments in cognitive function may lead to behaviours that pose a challenge to families and healthcare professionals and increase carer burden and they may lead to early institutionalisation.

These behaviours could manifest in a wide array of presentations including agitation/anxiety, verbal and/or physical aggression, disruptive behaviour, self-injurious behaviour, sexual behaviour, and wandering/absconding. In the case of Dementia, this could also present in an affective or psychotic picture.

Both entities are not considered diagnoses in of themselves but manifestations of unmet needs and/or a means to create sensory stimulation. Rarely are they the result of a specific factor but rather they arise from multiplicity of factors; biological, psychological, social, and environmental.

The mainstay line of management for both entities is person-centred, in which biological and psychosocial treatment approaches are pivotal. Support networks play a vital role in helping both groups.

Management of BPSD follows a basic stepped care model based on the severity of symptoms and the risks assessment (**Figure 1**). Rating scales such as CGIC, Pain Rating Scales, depression scales and delirium and confusion scales are employed in the assessment of BPSD. All patients presenting with these behaviours and symptoms usually undergo a medical review. Approaches to BPSD are highly individualised and take into consideration patients' backgrounds, interests, likes/dislikes, and needs.

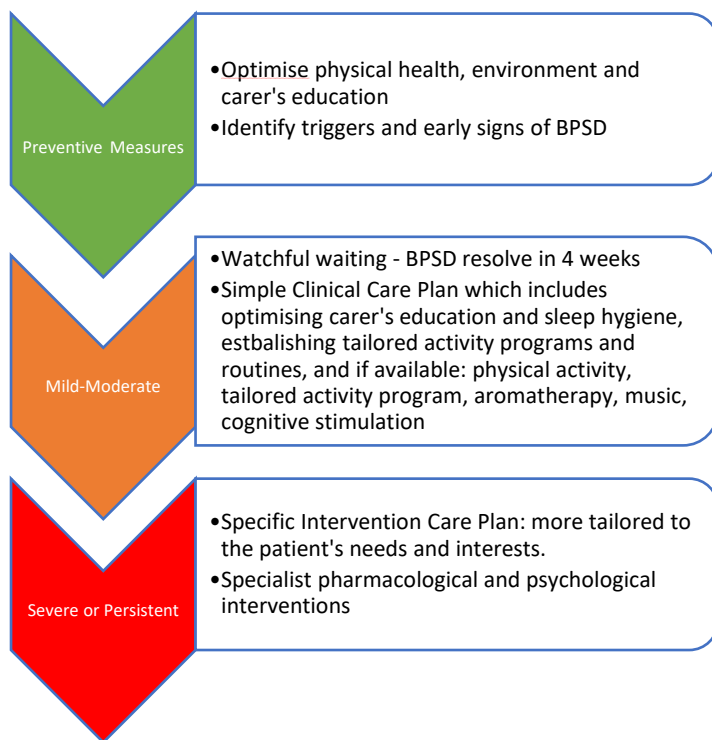


Figure 1: Basic stepped care model for management of BPSD in Dementia

Management of Behaviour that Challenges can also follow a basic stepped care model based on the severity of symptoms and the risks assessment. It aims to support the patient and carer to apply proactive treatment strategies and to attempt to substitute the idiosyncratic behaviours with pro-social ones. These treatments approaches are tailored to the individual's interests, needs and social networks. Hence, thorough assessments are imperative to aid approaches to these behaviours.

In both circumstances, when used, antipsychotic medications are generally a short-term management plan and patients are reviewed regularly with the aim of discontinuation of such medications. Symptoms, level of distress and risks are assessed and feedback from carers is noted leading to an ongoing care plan and recommendations regarding the discontinuation of antipsychotics. This would ensure patients are safeguarded against the antipsychotics' harmful side effects.

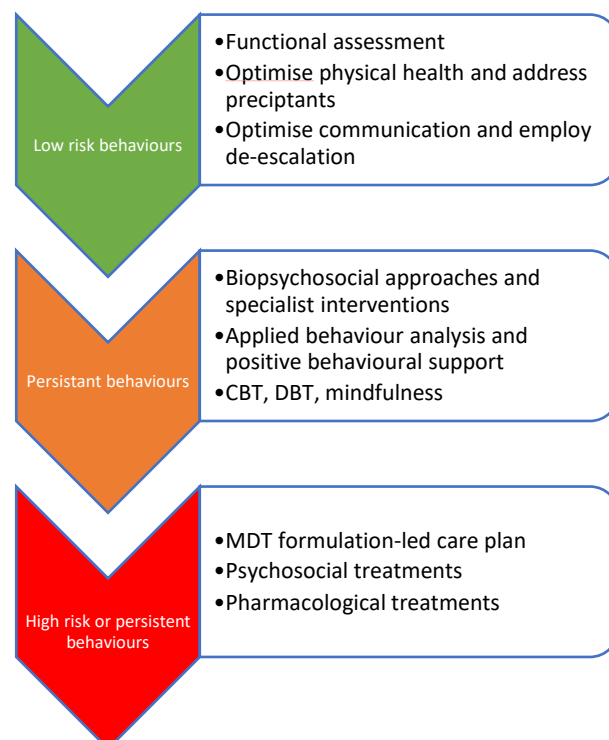


Figure 2: Suggested stepped care model for management of Behaviour that Challenges in ID

Given the overlap between both presentations, there is a compelling opportunity for learning across the Older Adult and Intellectual Disability psychiatric teams. I am currently working on a project to establish links between both psychiatric sub-specialities in order to share existing resources and ensure continued learning.

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Audit of Adherence to the "Annual Risk Acknowledgment Form" on the Sodium Valproate Pregnancy Prevention Programme ("Prevent")

Dr Avinash Jose, ST4 in Intellectual Disabilities, North Wales



An audit was completed, alongside Dr J York, Consultant Psychiatrist in Intellectual Disability, to look into the adherence to the 'Annual Risk Acknowledgment form' (ARAF) on the sodium valproate Pregnancy Prevention Programme ("Prevent") in Gwynedd, North Wales Adult Intellectual Disability Services.

Background

Sodium valproate is licensed in the UK for the treatment of epilepsy as well as for bipolar disorder. Both of these diagnoses are more common within individuals with intellectual disability than the general population, with mental illness in people with intellectual disability being twice as common as in the general population. Bipolar disorder exists at two times the rate in those diagnosed with intellectual disabilities. As well as the licensed uses, sodium valproate is sometimes prescribed to clients with an intellectual disability for the management of challenging behaviour.

The prescribing of sodium valproate in pregnant women has been reviewed in the UK for several years. Valproate is associated with a significant risk of congenital disabilities and developmental disorders in children born to women who take valproate during pregnancy. In recent year the Medicines and Healthcare products Regulatory Agency (MHRA) has strengthened regulations governing its use: the pregnancy prevention programme, (PPP), is a core component of these regulations. The implementation of the regulations is central to reducing the harms associated with valproate use in pregnancy and in women of childbearing potential. The annual risk review

is part of the PPP, designed to mitigate the risk.

Patients should be involved in this process, even when they lack capacity to consent to treatment. Within the review, discussion with the family and the care providers to evaluate if sexual relationship & activity is likely to occur or not is recommended. If it is agreed that the risk of pregnancy is unlikely, ARAF should be completed. It should be clearly documented in clinical notes and be reviewed at least annually, or more frequently where there are changes in circumstances.

"Prevent" is the pregnancy prevention programme by Medicines and Healthcare products Regulatory Agency (MHRA) published 24th April 2018.

- The MHRA 'Prevent' guide is about the prescribing and continuation of Valproate to girls (of any age) and women of childbearing potential
- It discusses risk minimisation measures which are part of 'Prevent' - aimed at minimising pregnancy exposure during treatment with sodium valproate.

"Prevent" guidance for Specialists:

- Discuss the risks with the patient (or parent /caregiver /responsible person)
- Exclude pregnancy in women of childbearing potential by serum pregnancy test before the first prescription
- Arrange for highly effective contraception for women of childbearing potential before the first prescription
- Complete the Annual Risk Acknowledgement form with the patient (or parent /caregiver /responsible person). Give them a copy and send a copy to the GP
- See the patient urgently within days if referred back in case of unplanned pregnancy or wish to plan a pregnancy
- Provide a copy of the Patient Guide to the patient (or parent /caregiver /responsible person)

Aim & Objective

To assess local practice compliance with "Prevent" Annual Risk Acknowledgement Form completion for patients within the Intellectual Disability service who have been treated with sodium valproate for their mental illness, and to evaluate how close local practice is to best practice. The ultimate objective is to enhance compliance locally in order to improve patient care and those safety measures aimed at minimising pregnancy exposure during treatment with sodium valproate.

Methodology

We retrospectively collected data reviewing Gwynedd Inpatient and Community patients' Clinical Notes who were treated with sodium valproate for mental illness between 1st January 2022 and 1st February 2023. We reviewed the presence of the Annual Risk Acknowledgement Form in the notes, the compliance with this and the three steps leading to completion.

Results

On analysis of the collected data from Service Users' Clinical Notes we found:

- There were 7 patients prescribed sodium valproate, of which 43% were male and 57% female (see Figure 1).

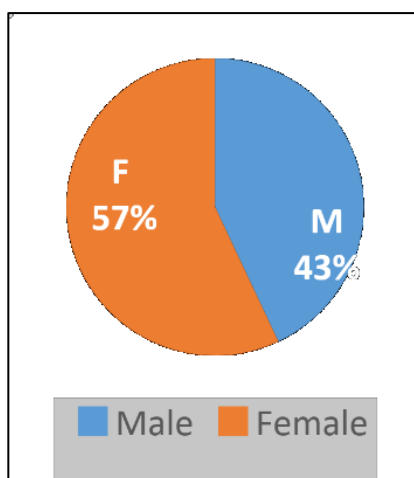


Figure 1: Percentage of service Users according to their gender

- 71 % patients were between the ages of 15 to ≤ 55, and 29 % were over 55.
- Sodium valproate was initiated in 57% for treatment of bipolar affective disorder, 14% in relation to challenging behaviour and 29% with due to a combination of challenging behaviour and mental illness (see Figure 2).

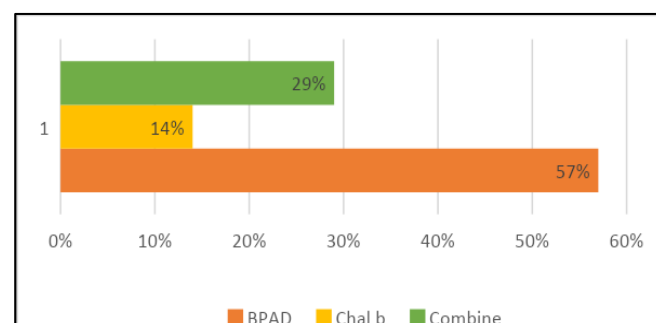


Figure 2: Percentage of Service users on Valproate for Indications Bipolar affective Disorder (BPAD), Challenging Behaviour (Chal b)& Combined (Combine)

- A trial of another mood stabiliser before sodium valproate was confirmed in 14% of cases, with the rest having not tried another mood stabiliser (68%), or there was no evidence either way/the reviewer was unsure (18%).
- Every service user on sodium valproate had an Annual Review (100 %).
- Regarding the Annual Risk Acknowledgement Form, 14% of patients had one found in their records and 28% of patients were not required to have one. There was no evidence of a completed Annual Risk Acknowledgement form, in the remaining 43% of patients' records. It is unknown if any patients were given a copy of the form as this was not evident in any notes (see Figure 3).

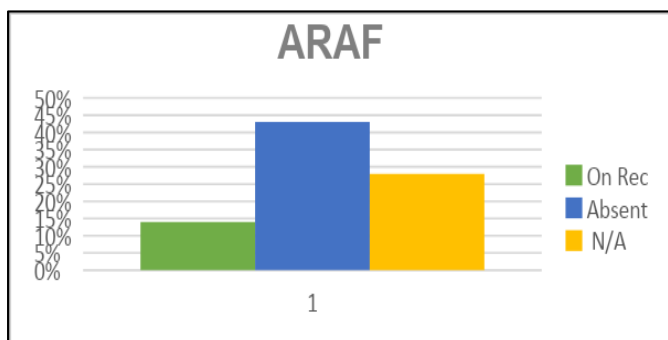


Figure 3: Percentage of patients with Annual Risk Acknowledgment form in notes (On Rec) , not in notes (absent) or if not applicable (N/A)

- For 14 % of service users a copy of the form was sent to their GP; the rest 86 %, did not require it to be sent.
- Regarding the quality of form completion, 14% of patients' forms were fully completed to a good quality, whilst 28% did not have a form, and the remaining 58 % did not require a risk acknowledgement form.
- There was no evidence in any notes to suggest whether a pregnancy test was carried out prior to first prescriptions being administered.
- While 28% of patients were on some form of contraception, a further 28% were not. For the remaining 44% of patients, this was not applicable.

Conclusion

Every service user on sodium valproate underwent an Annual Review. Although 43% of female clients on sodium valproate were of child bearing potential, only one-third of them had evidence of an Annual Risk Acknowledgement Form fully completed to a good quality within their clinical notes. 43% were also on contraception during the review period.

The recommended plan moving forwards is to increase awareness and education through joint meetings & discussions amongst specialists within Intellectual Disabilities Services about the importance of the completion of the Annual Risk Acknowledgment Form. Furthermore, the service will be re-audited next year.

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CAMHS LD STOMP Audit

Dr Annie Swanepoel, Consultant Child and Adolescent Psychiatrist

SET CAMHS Learning Disabilities Team



Background

NHS England recognised that children with intellectual disabilities are too often medicated inappropriately with antipsychotic and other psychotropic medication and launched Supporting Treatment and Appropriate Medication (STAMP) for children, to build upon the Stopping Over-Medication of People with learning disability and/or autism (STOMP) initiative.

Attention-Deficit Hyperactivity Disorder (ADHD) is a relatively common comorbidity in children with a severe and profound learning disability. Paediatricians are commissioned to diagnose and treat ADHD across Essex. There is a large wait list for such children for ADHD assessment, and a treatment waitlist for those with an ADHD diagnosis. Due to current commissioning arrangements, it is difficult to get ADHD medication prescribed through paediatrics because of the long waiting lists.

When such children have presented in crisis, psychiatrists have prescribed antipsychotic medication, primarily to address risks and challenging behaviour. This practice is not in the best interest of the child, as it means that the antipsychotic medication ends up being used in the longer term, masking the ADHD symptoms of hyperactivity and impulsivity, without treating the symptom of inattention effectively.

Antipsychotic medication can also cause significant metabolic side effects and requires monitoring including regular blood tests, which is often difficult in this population, and hence has potential to lead to harm.

Summary of findings

In 2021, the CAMHS-LD Consultant Psychiatrist reviewed the total psychiatric

caseload in the team that was handed over by the predecessor psychiatrist (locum) in February 2021. There was a total of 59 patients, of whom 14 had a diagnosis of ADHD and were treated for it, another 14 had a diagnosis of ADHD, but were not medicated, and an additional 31 were either awaiting ADHD assessments or had not been referred for an assessment.

Upon re-auditing the caseload 2 years later in 2023, there were a total of 52 cases, of whom 30 had a diagnosis of ADHD and were on treatment, another 6 had a diagnosis of ADHD and were not treated. The remaining 16 had no diagnosis of ADHD. This is in keeping with the literature that confirms that the greater the degree of learning disability, the greater the likelihood of ADHD with 69% of the caseload having the diagnosis (compared to 47% two years ago).

It is helpful to see that the rate of ADHD diagnosis (from 47% in 2021 to 69% in 2023) and treatment for ADHD (from 50% in 2021 to 83% in 2023) increased substantially over the past two years.

Areas of improvement

In 2021, almost 25% (14/59) of the psychiatric caseload involved children with ADHD who were not treated for ADHD. Of these, more than half (8/14) were treated with antipsychotic medication for challenging behaviour. This is not in the best interest of the child, as antipsychotic medication is associated with significant long-term metabolic complications and therefore requires 6-monthly blood tests. Of these 8 children, only 1 had a blood test within the previous 6 months, partly because the recent pandemic related disruptions

and in part because blood tests are difficult for these children owing to resistance.

In 2023, only 12% (6/52) of the psychiatric caseload involved children with a diagnosis of ADHD who were not treated for it. Of these 6 children, 3 (half) were treated with antipsychotic medication. In all three cases the parents refused to consider reducing the antipsychotic medication – one because it was started by a specialist tertiary team and they did not want any changes made, and the other two because ADHD medication had not been successful in the past. In all three cases their blood tests were up to date as per NICE-guidance. Of the other 3 children, 2 had been on stimulant medication and had a bad reaction to it, which made the parents unwilling to try anything else and the third had not had a response to ADHD medication that had been tried in the past.

Lessons Learnt

If children with severe/profound learning disability are not assessed or not treated for ADHD and present with challenging behaviour, they are more likely to be prescribed antipsychotic medication to manage risk associated with self-harm or violent behaviours. This is not in the child's best interest.

According to the NICE-guidance, the prescription of antipsychotic medication in children with learning disability should be the last option and should only be prescribed in conjunction with a behaviour plan and strict monitoring. Antipsychotics work to subdue children and to a certain extent they also subdue children with ADHD by reducing the symptoms of hyperactivity and impulsivity (but not treating the inattention, and hence children continue to struggle in academics).

When antipsychotics are withdrawn, the ADHD symptoms come back, and the children then appear to need antipsychotic medication for long periods without further assessment or treatment of ADHD, as the child does not have the core symptoms of hyperactivity and

impulsivity due to the antipsychotics acting to subdue the child.

ADHD is extremely common in children with a severe learning disability and can be treated with medication that specifically targets ADHD symptoms and which does not require blood tests. It is hence recommended as good practice for all children with a severe learning disability to have an ADHD assessment as routine, at baseline, prior to CAMHS referral. This should be a minimum requirement before antipsychotic medication is considered for challenging behaviour, as unmedicated severe ADHD may be the underlying cause of behaviours that challenge.

The Author has given several invited lectures to paediatricians across Essex. One of these talks: "Challenging behaviour in children with LD: are we missing ADHD?" was recorded and is freely available at [ADHD in children with learning impairment: are we missing the diagnosis? \(synapsecentre.co.uk\)](https://www.synapsecentre.co.uk/adhd-in-children-with-learning-impairment-are-we-missing-the-diagnosis/).

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Challenges in STOMP and physical health inequalities in Intellectual disability during pandemic

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Scunthorpe, Rotherham, Doncaster and South Humber NHS Foundation Trust



As we enter the third year since the first lockdown with COVID-19 was announced, it is important that we reflect upon its impact on our patients and services. Intellectual Disability teams have had to make reasonable adjustments to support the patients, while minimizing risk of COVID transmission.

Challenges faced by people with Intellectual disability during the pandemic

Isolation:

Due to the increased prevalence of physical health problems in people with intellectual disabilities, they were classed as a 'high risk group' and needed isolation. This resulted in a lack of structured activities, due to the closure of day centres. Lack of activities resulted in an increase in challenging behaviours. Families struggled to have the regular input from carers and had no respite options. In some cases, people living in care homes were unable to visit family or have family visit them, which had a huge impact on their mental health.

Changes to routine:

Confusion around evolving changes to restrictions and the use of masks caused anxiety amongst carers and people with intellectual disability.

As cases rose, there was an increase in COVID-19 infection amongst staff, last minute changes to carers and, sometimes, minimal staff to cover care homes. This, again, resulted in an increase in anxiety and behaviours that challenge.

Physical health:

Routine physical health monitoring has also been difficult due to patients having to isolate.

Hence, physical health problems, such as diabetes, were not monitored as regularly as one would expect them to be. Some patients were on a long waiting list for dental treatment, elective surgery, etc. This resulted in them being in pain and, understandably, resulted in behaviours that challenge.

Grief:

Many lost their family members and peers during the pandemic. However, many of those with intellectual disability did not have the cognition to fully understand the problem, which caused fear about illness and death.

Changes to restrictions:

When the restrictions were finally lifted and day centres and shops opened, many struggled to come out due to fear and changes to routine again. During restrictions, some people with autism coped well as they did not have to face sensory overload. So, when they started coming out of the 1 year of routine, it caused anxiety and challenging behaviours.

Adaptations by intellectual disability services in making medication reductions under STOMP guidelines

In North Lincolnshire, we set up separate clinics for Stopping the Over-Medication of People with Intellectual Disabilities and/or Autism (STOMP). Our community learning disability team has been resilient and worked hard to ensure that physical health problems

were managed, and the STOMP agenda was not forgotten during the pandemic.

The lack of regular physical health monitoring resulted in an increase in emergencies. Poorly controlled diabetes, increases in constipation due to sedentary lifestyle, and pain due to a lack of dental treatment contributed to behaviours that challenge. Carers turned to community learning disability teams for both pharmacological and non-pharmacological management of the behaviour. Our community team played a key role in liaising with other services to manage physical health issues. In some instances, carers struggled to understand that we were not quickly fixing the behaviour by providing psychotropic medications. In such cases, psychoeducation for the carers of the impact of physical health on behaviours were provided and the unwanted side effects of the medication had to be explained.

Nurses had to liaise with social care colleagues to provide some respite and reduce the burden on carers. When the restrictions were lifted, advice around the gradual introduction of activities were provided to minimise sensory overload.

Physical health liaison nurses ensured that everyone had their annual health check review when the pandemic restrictions were lifted. (1)

When medications were reduced under STOMP guidelines, there were difficulties in supporting with positive behavioural support plans due to restrictions, lack of activities etc. This meant that people needed increased support from the community team. Where necessary, the community team provided increased support via telephone call or face to face.

Above all, psychoeducation around STOMP has been provided by sending leaflets, discussions in the clinic and multidisciplinary meetings. Despite all the hurdles, we had been successful in continuing to implement the STOMP agenda during the pandemic.

Conclusion:

The team continue to strive to meet their goals of deprescribing through safe and controlled limits. In some cases, they have made it possible to reduce some medication, with constant efforts to reduce more. This has also

improved the patient-carer relationship and physical health needs are addressed better. We are confident that this initiative will continue to provide a better quality of life for our patients.

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Lost in Translation

Dr Alaaelrahman Shahib

Psychiatry CT1



As I walked into the conference room, I felt like a lost traveller in a foreign land. My dark skin and heavy Egyptian accent seemed to mark me as different, and I couldn't help but feel self-conscious. Even the simplest of phrases, like "are you alright?" could be confusing, since in my native language it often meant "do you need help?" When someone asked me that question, I thought I must have looked lost and disoriented.

My heart raced as I found a seat in the back of the room, hoping to avoid drawing attention to myself. But as the speaker began to talk, I realised that my struggle with language was going to make it difficult to keep up. The words seemed to blur together, like a puzzle I couldn't quite piece together. My ears and brain were working overtime to understand the accents and background conversations around me. I tried to focus on the lecture, but it was so challenging.

And then, a voice broke through my anxiety, and I felt a glimmer of hope. "You alright?" my colleague asked, as she was sitting down next to me, but as I worked to form a coherent answer, I realised she wasn't expecting one. The question hung in the air, like a cruel reminder of my efforts to understand the meaning behind words, and I felt a surge of frustration and despair.

As I sat there, feeling lost and alone, I couldn't help but think about those who face similar barriers every day. Those who live with intellectual disabilities and must navigate a world that often doesn't understand them. I thought about how their brains must work extra hard to understand and process information, and how even the most mundane

conversations can feel like an insurmountable challenge.

My mind wandered to a patient I once cared for who had an intellectual disability and struggled to communicate effectively. He often felt isolated and misunderstood, as if no one could hear his thoughts or feelings. His frustration and desperation were palpable, and it was heart-breaking to see him battle through these feelings.

In that moment, I realised that my own obstacles had given me a unique perspective. My experiences of feeling like an outsider had taught me the value of empathy and understanding. I thought about how those with intellectual disabilities might experience social isolation, and how even a simple act of kindness like asking "are you alright?" could make a difference.

As the speaker's words continued to wash over me, I realized that language wasn't the only barrier to understanding. People with intellectual disabilities face multiple barriers every day, including stigma, discrimination, and a lack of appropriate accommodations and support. They often have difficulty communicating their thoughts and feelings, which can lead to frustration and loneliness.

I felt my heart wrench as I reflected on the immense struggle of those with intellectual disabilities. The pain of feeling unheard, the frustration of not being able to express oneself, and the isolation that often accompanies it all. Yet, in that moment, I also felt a sense of hope. A hope that by sharing my own struggles, I could create a space where others felt comfortable sharing theirs. Although my struggles were not the same as those faced by my patient, they had taught me the value of patience, persistence, and empathy. They had

shown me the importance of reaching out to others, even when it felt uncomfortable or challenging.

As a psychiatrist, I am committed to using the hurdles I experience myself to help people with intellectual disabilities. To listen, to empathise, and to create a space where everyone feels valued and accepted, regardless of their abilities or disabilities. I may have arrived in the UK only a month ago to start my psychiatry training, but my own experiences have already taught me that our challenges are what make us unique, and that it's our job to use those struggles to help others.

In the end, I realized that the question "are you alright?" was more than just a greeting. It was a reminder that we all have trials to overcome, and that it's okay to ask for help. By embracing our own challenges and reaching out to others, we can create a more inclusive and empathetic society where people with intellectual disabilities are seen, heard, and valued.

A Personal Reflection on Services for People with Intellectual Disabilities in Sudan

Dr Aisha Motwakil Bakhiet

Consultant Psychiatrist; Head of department Psychiatry, University of Khartoum



Background

Sudan, classified as a lower middle income country (LAMI) has witnessed political unsettlement over the years. Moreover, economic hardship has worsened access to health services. The WHO mental health atlas 2011–2012 stated that only 55% of LAMI countries have mental health legislations [1]; the proposed Sudanese Mental Health policy has been awaiting to be passed as legislation since 2018. Health expenditure is only 1.6% of the country's budget. The expenditure on mental health is unknown [2].

According to the 2008 census, there were 1,463,034 Sudanese with disabilities (4.8% of the population). Children aged 5 to 14 were the group most likely to have disabilities (14.9%). However, there were no specific statistics for intellectual disabilities (IDs) [2].

Only 38% of persons with disability aged six and older are enrolled into schools, 15% have previously attended school at some point and 41% have never attended schools. Fifty percent of working age disabled people are employed [2]. People with disabilities face challenges including access to health, support, rehabilitation, education, as well as employment [3].

Obstacles to services for people with intellectual disabilities include lack of reliable statistics, and governments and decision makers do not give sufficient priority to services for the disabled.

Perception of Intellectual disability in Sudanese culture

The Sudanese community is a reserved community with a very close social fabric and strong religious beliefs. Fear of stigma against mental illness prevents many families from accessing treatment [4]. Stigma against disability in general constitutes a great obstacle to early help seeking. Traditional healing is more culturally accepted than going to see a psychiatrist. Interestingly, some communities perceive disability as a sacred sign from God and can lead to exploitation of people with disabilities by people coming to them seeking blessings. This can prevent families from seeking health care or education as they rely on the person's disability as a source of income.

Current situation

There are three main psychiatric hospitals providing lifelong service in Sudan; all of them are in the capital Khartoum. There is only one Intellectual disability Psychiatrist in Sudan placed in Khartoum. There is no clear referral pathway and no proper multidisciplinary team work. Despite the scarcity of services for disabled children, most of them are clustered in Khartoum.

Mental health services and rehabilitation centres for people with an intellectual disability are very scarce and are provided by individual initiatives, mainly by the private sector. This magnifies the problem of inadequate access to interventions and support, particularly for poor families. Most specialized schools for children with an intellectual disability are owned and run by parents of disabled children. These centres provide services across the lifespan

for children and adults with intellectual disabilities who usually share the same facilities including toilets, which increases exposure and vulnerability to abuse. There is no governmental supervisory body and no protocols or guidelines to govern these schools. Furthermore, the staff are poorly paid with no formal training and no evidence-based practice.

Highlights of personal achievements for patients with intellectual disabilities

- Since my return to Sudan in 2009, I have worked as a Consultant Psychiatrist in Taha Baashar Psychiatric Teaching Hospital; one of the main three Psychiatric hospitals in Khartoum. It is a second tier service for adult psychiatric patients.
- I have established a Child Psychiatric unit as well as a CAMHS-LD service; as a weekly outpatient clinic for children with intellectual disabilities and other psychiatric problems. Referrals come from all disciplines including Health and Education across the country. This service has gained a wider reputation across Sudan and has helped many families to cope with their children's problems of varying nature and severity.
- I participate in raising awareness about mental illness among the public through the media and as part of educational events and seasonal celebrations like World Mental health day, Autism day, Fighting stigma of mental illness...etc.

This article has highlighted some of the challenges as well as the individual efforts that have improved the lives of Sudanese people with intellectual disabilities; giving a glimpse of hope for a better future to these patients and their families.

In the absence of robust research, the current evidence is derived from descriptive studies and clinical reviews.

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Insight into Intellectual Disability

Dr Asma Ambreen
ST5 in Psychiatry of Intellectual Disabilities

Altruism, empathy, and sympathy drove me towards the field of mental health. I have always been fascinated by the diverse workings of the human mind. I understand that being a psychiatrist is a demanding job as it requires us, as professionals, to understand people's ideas and emotions; humans are a supreme creature, but they are the most complicated ones when it comes to emotions and thoughts.

I chose to work in mental health because I enjoy untangling people's thoughts and providing solace to people in times of need. My fascination with the field of psychiatry began in the early years of my medical education when I felt an inclination towards understanding people's feelings, relationships, and emotions. The only aim so far has been to make a difference in society by playing my role; I feel I have been given so much and I wish to play my part and give back as a responsible member of the community.

Being an overseas trained doctor, working in the UK has not always been easy for me. Even after working in psychiatry as a Specialty Doctor and later as a Core Trainee, I could not fully comprehend the concept of intellectual disability. I remember discussing it with people around me and finding that the overall impression was negative. 'Challenging' and 'difficult' were amongst the terms used to describe working in the specialty. However, despite this, my interest continued to grow. I was quite enthusiastic as a Core Trainee and made sure that I took any opportunity that came my way to learn about intellectual disability.

I was fortunate to have a rotation in an inpatient intellectual disability unit. I must admit, it was an overwhelming experience and

I felt out of my comfort zone. In the beginning my belief of being able to help the patients was shaken, I had to reconsider if I was the right person for the job. Observing the work of the multi-disciplinary ward team soon allayed my fears and the psychiatry world began to make sense to me again. I was impressed to see how skilled these professionals are and what a positive difference they can make to people in vulnerable situations.. I was inspired by the teamwork, dedication and commitment of my colleagues and by how the team took the patient's and family concerns into account. I was reminded of the phrase:

'It takes very special people to understand the person behind a patient, to listen to what is unsaid, see what is unapparent'

As my experience with service users grew, I realised how important it was to have effective communication skills, to see the whole person, and to work with them on their treatment plans. I found the work could be emotional as sometimes people shared their experience of being maltreated. Many expressed their gratitude to professionals for listening to them and for being kind. It felt good that we had in some way contributed to their well-being.

The opportunity to work with individuals with intellectual disability opened another horizon for me and I knew it was my calling. Providing support, education and empowering individuals with intellectual disability to be independent and involved in their community gives me a sense of pride and fulfilment and makes the job rewarding.

Medical Student Experience in Intellectual and Developmental Disability Services

Jesmine Dhooper, medical student

Nottingham University



Whilst choosing a student selected module, I was drawn towards psychiatry for a number of reasons, which include the unique level of insight psychiatrists have into the lives of their patients and the trusting relationships built in order to best support them. In previous placements, I had not experienced working with individuals with an intellectual disability. This population often face high levels of health inequalities and have multiple barriers in accessing healthcare (Emerson, 2022; Dunn et al 2018), so I felt it would be important to learn more about their health needs and to understand the differences in their presentations and the treatment of common comorbidities.

Whilst on my Intellectual and Developmental Disability (IDD) placement, I observed a Speech and Language Therapy (SALT) assessment of a 26-year-old male, Patient X, with moderate intellectual disabilities (ID). Patient X underwent a Test of Abstract Language Comprehension, an assessment used in children 2+ years to test understanding of concrete and abstract language. I realised the importance of these assessments when Patient X was getting frustrated at staff as they could not always understand if he wanted medication or his favourite drink.

To help overcome this, the SALT team produced a keyring with pictures of items of food, medicine or emotions that would aid in his communication with staff. This was designed at an appropriate level for him to understand, helped minimise misunderstandings and was provided reassurance to Patient X. I also saw the use of easy read resources e.g. social stories of an appropriate level to further help Patient X to process information and limit confusion.

Through this, I appreciated the importance of adopting a total communication approach, including using signs, gestures, pictures and words to improve our patients' quality of life and to ensure their needs and wishes are respected.

I was fortunate to see patients with common co-morbidities associated with ID, including autism spectrum disorder (ASD), attention deficit hyperactivity disorder (ADHD) and epilepsy (4), and observe how approaches to diagnosis and treatment may have to be adapted. For example, Patient X, who had a concurrent diagnosis of ASD, presented differently and benefitted from different psychosocial interventions to Patient Y, a high functioning ASD patient who was currently completing a PhD. While Patient Y was able to explain and articulate his symptoms and had better engagement with screening questionnaires e.g. an AQ10, Patient X's ASD screening consisted of observing for characteristic ASD behaviours, such as difficulties in reciprocal social interaction or the presence of marked repetitive activities e.g. finger flapping under stress, and obtaining a detailed initial history from parents or carers. Both cases would then be referred to secondary services for further specialist assessments.

Interventions may also vary, including psychosocial interventions, as different group-based or individually delivered programs are recommended depending on each individual's functioning, needs and the presentation of challenging behaviour (NICE, 2020). For example, Patient Y, was offered a 6 week college training program to learn more about ASD, whereas this educational intervention would not be suited to the literacy needs of Patient X. Instead, it might be more helpful to

establish a routine and consider medication if agitation was a problem. Therefore, it is important to have an awareness of these different presentations and assess each patient, whether with or without an IDD, as an individual so that they get the best support plan that is tailored for them.

Furthermore, I had the opportunity to attend an IDD epilepsy clinic, a specialist service where I met Patient Z, a 25-year-old female with Rett syndrome. She experienced tonic-clonic seizures, tonic seizures, absence seizures and abnormal movements of her left arm, which were thought to be behavioural. Through Patient Z's consultation, I came to appreciate the challenges in making an epilepsy diagnosis for individuals with IDD, as they may not be able to give a full detailed history of the event. Therefore, throughout the consultation, we obtained second hand observations from Patient Z's carer, adding another layer of complexity to diagnosis and monitoring of treatments for this comorbidity.

Finally, throughout my placement I came to widely appreciate more about inpatient and outpatient care of those with an IDD. I found inpatient work to be particularly interesting as patients had a lengthy period of time with access to a range of professionals in order to best understand how they could be supported, often through the creation of detailed patient formulations. I believe that this type of approach to patient-centred care can be very rewarding and stimulating, as it can produce massive positive impacts upon quality of life.

It was also insightful to discuss discharge plans for patients, as I began to understand the complex and lengthy process required to ensure that the patient both understood and were happy with their care plan. This ensures that they are given the best chance of settling at home or into community placements.

In conclusion, I would encourage every medical student to seek some placement working with individuals with an IDD to gain an awareness of their communication and comorbidity challenges and learn to facilitate

meaningful interactions. This would ensure that we can offer the best support and quality of life possible to our patients and their care network.

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Joint Pan-London Forensic & Intellectual Disabilities Psychiatry Conference

Dr Gillian Brown, ST4 in Psychiatry of Intellectual Disability



On Friday 24th March, around 50 delegates gathered in the ornate Old Library in the Garrod Building, Whitechapel, for the first Joint Forensic and Intellectual Disability Psychiatry Conference.

Dr Nicole Eady (Consultant Psychiatrist and North London Training Programme Director) welcomed attendees to a day of informative and thought-provoking sessions on topics relevant to both specialities.

Gilded Cages: Deprivation of Liberty Safeguards (DoLs) in Practice

“A gilded cage is still a cage” – Lady Hale

Dr Shakeel Islam (Consultant Psychiatrist, John Howard Centre and Newham Community Team) and Dr Sanjay Nelson (Consultant Psychiatrist, John Howard Centre and Clinical Director for East London Intellectual Disability services) opened the day with a session on the Mental Capacity Act (MCA) and DoLs, using clinical vignettes and case law to illustrate some of the nuances and intricacies, including the expected changes within the long-awaited Liberty Protection Safeguards.

Attendees engaged in enthusiastic discussion about challenges encountered in practice, including decisions to use the MCA instead of, or as well as, the Mental Health Act (MHA) and the extent to which risk to others could be considered when making best interest decisions. The session ended on a hopeful note, with the case of a challenging, but ultimately successful, discharge.

Challenges in Diagnosis of Autism Spectrum Disorder (ASD)

Dr Laura Humphries (Consultant Psychiatrist, Tower Hamlets ASD Service and Community Team) provided a helpful overview of the diagnosis of ASD, including tools and the differences between ICD-10 and ICD-11 diagnostic criteria, including atypical sensory processing as a core feature, and removing the requirement for evidence before the age of three (closer to DSM-V criteria).

Dr Humphries spoke about the increased prevalence of co-morbid mental illness in people with ASD and discussed the challenges of diagnosis both in the general population and within forensic and intellectual disability services.

The session was well received, generating discussion about draft legislation to reform the MHA and the potential implications for practice. The future shape of services for diagnosis and management of ASD was considered, including developing specialised services as well as expanding capacity across general psychiatric services.



ASD in Forensic Settings

The following session by Dr Anna Rahman (Consultant Psychiatrist) and Dr Guy Ansah-Palmer (Specialty Doctor, John Howard Centre) developed and built on ideas from Dr Humphries' session.

Dr Rahman spoke about the challenges of diagnosis within forensic settings and on the interplay between ASD and offending, contrasting the impaired understanding of theory of mind with the lack of empathy seen with psychopathy (the difference between "not understanding" and "understanding but not caring").

Dr Ansah-Palmer provided an overview of the Transforming Care Programme (set up in 2015 in response to the Winterbourne View scandal). This generated broader discussion about more recent revelations of abuse including at Whorlton Hall in 2019 and Cygnet Yew Trees in 2020. The group reflected on the importance of remaining vigilant for further abuse and considering the consequences, both intended and unintended, brought about by wide-scale changes to services. This provided helpful context for the case presentation which illustrated complexities and challenges in formulating and managing risk of further offending (in this case, arson). Issues such as the limited availability of specialist placements were recognised by many attendees.

Dr Rahman reminded the group of the value of the multidisciplinary team input and of the importance of focusing on the individual person and circumstances, summarising with the quotation: "If you've met one person with autism, you've met one person with autism" – Dr Stephen Shore

Lunch

"One cannot think well, love well, sleep well, if one has not dined well" - Virginia Woolf

Attendees enjoyed hot drinks, delicious food and sweet treats which helped sustain focus and fuel enthusiastic debate throughout the day. Leftovers were shared with the local Whitechapel Mission food bank.

Forensic Neurodevelopmental and Intellectual Disabilities Service

Dr Robert Farrelly (Clinical Psychologist) and Dr Rory Sheehan (Consultant Psychiatrist, South London Forensic Intellectual and Neurodevelopmental Disabilities Team), presented a case which illustrated complexities including diagnostic uncertainty.

Practical issues such as obtaining collateral information and historical records, working between different services (including social care and criminal justice) and trying to provide psychological interventions in chaotic environments felt familiar to attendees. The links between the formulation (including attention deficit hyperactivity disorder) and the risk of offending was considered using the HCR-20 risk assessment tool.

The group discussed the implications of fitness to plead outcomes and differences between hospital settings and prisons with adaptations, with passionate debate regarding the role of anti-libidinal medication and the use of clozapine to manage aggression and violence.

Psycho-Legal Workshop

Dr Richard Latham (Consultant Psychiatrist, Tower Hamlets Forensic Outreach Service and Clinical Director of the North London Forensic services) ended the day with several cases demonstrating the complex interaction between ASD, offending and the criminal justice system.

The first case considered issues associated with using autism as a legal defence and philosophical questions regarding morality and free will. This led to further discussion around the question: “is autism a mental disorder?” and the implications for mental health and criminal law associated with the proposed changes to the MHA.

The second case highlighted ethical issues encountered when working as an expert witness, particularly if working within legal systems which use the death penalty. The final case considered issues associated with the diagnosis and management of young people, specifically the interaction emerging personality disorders and ASD.

Conclusion

The day's sessions generated plenty of discussion about ethics, philosophy, law and medicine, as well as more practical issues associated with providing care in the context of complex (and resource-limited) legal, health and social care systems. All-in-all – a great success!

Thank you to the organising committee:

- Dr Amgad Atia (ST5, West London)
- Dr Vishni Balakrishnan (ST4, East London)
- Dr Max Hudson (ST5, West London)
- Dr Emma Khosla (ST4, South London and Maudsley)
- Dr Hannah Rollmann (ST5, East London)
- Dr Dong Seok Lee (ST6, Oxleas / West London)

Prizes and Bursaries

ID Faculty educational bursary

An educational bursary fund is available for doctors in training 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 trainees and SAS doctors

ID Faculty: Bursary for psychiatrists from LAMI countries

A bursary to enable a psychiatrist from a low- and middle-income (LAMI) country to attend our annual residential meeting (usually held in the autumn) to give an oral or poster presentation, or deliver a workshop. The bursary is designed to cover the cost of economy class travel, accommodation, free registration and attendance at our conference dinner, up to a maximum of £1,500.

Deadline: 31 May 2023

ID Faculty: Joan Bicknell Medical Student Essay Prize

Deadline: 1 December 2023

Prize: £250 and subsidised attendance at the faculty conference

Eligible: medical students in the UK

ID Faculty: Gregory O'Brien Travelling Fellowship

Deadline: 31 December 2023 (awarded biannually)

Prize: £1,000

Eligible: Applicants must be in an approved UK training scheme working at CT1-ST6 level, or be within the first three years of a consultant post to enter.

CONGRATULATIONS 2022 PRIZE WINNERS

2022 Alec Shapiro Prize

Dr Sonya Rudra (oral)

Dr Shaya Mufti (poster)

2022 Jack Piachaud Medical Student Poster Prize

Megan Hunt



Submitting articles: This is the 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 in the RCPsych Intellectual Disability Faculty. The Editor reserves the right to edit contributions as deemed necessary.

Copyright of submissions are retained by its author, but the College reserves the right to reproduce the article on the Faculty website pages.

Join the Editorial Team! The Editorial Team also welcome expressions of interest to join us on the team. This can be team members of any level. Please do send a paragraph about yourself, why you would be keen to join the editorial team and what previous relevant experience you have.

Any queries, submissions or expressions of interest to be sent to newsletter.psychid@gmail.com

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