Psychiatry of Intellectual Disability

Newsletter of the Intellectual Disability Psychiatry Faculty

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CONTENT

Submitting articles: This is the Faculty members' newsletter and we encourage submissions from clinicians, students, service us-ers, carers and members of the wider multidisciplinary work-force. 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.

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

Any queries, submissions or expressions of interest should be sent to **newsletter.psychid@gmail.com**. We would appreciate your feedback and correspondence.

Editorial Committee Members

Editorial

Dr Maruf Mustapha & Dr Rachel Proctor

Co-Editors for Winter 2023 edition

Welcome back to the winter edition of the intellectual disability psychiatry faculty newsletter. We are pleased to be able to follow up on the very successful spring edition, and we hope to maintain the high standards that were set. We hope to continue publishing this biannual newsletter in a timely and helpful format.

While we considered making a few improvements to the format, due to time constraints and the need to maintain some consistency, we would instead be implementing these changes for subsequent editions. These include hosting people with lived experience as guest columnists and having them as editorial panel members, as well as utilising the burgeoning power of AI to make easy-to-read summaries and visual captions of the articles. Look out for these changes and more in subsequent editions.

In this edition, we have captured a diverse range of topics, starting off with a key interview with the faculty financial officer, Prof. Mahesh Odiyoor. In this interview, he discusses his personal and professional capacities, his roles and partic-ipation in the faculty, and his outlook for the future of the faculty.

We also hear from the incoming ST reps, Dr David Anderson and Dr Abigail Swift. Amongst many things, they highlight the impact of insufficient inpatient units on ID training, the experiences using the new portfolio, and changes to the curriculum. This is followed by a message from Dr Mary Bar-rett, the immediate past chair of the ID Specialty Advisory Committee, who gave an account of developing, imple-menting and early appraisals of the run-through ID training program, which has been well received.

We were privileged to receive an article from the Mother of a person who lived with learning disabilities. The author highlights some of the ups and downs of being a caregiver, their journey around navigating access to care, and a few life lessons they learned from their daughter, leading to successful advocacy for systems changes. This was an inspirational article to read.

Also in the same vein, one of our colleagues in the faculty, who has a unique point of view of also being a patient, shares her experiences and opinions around cess to a seemingly beneficial but restricted medication. This article about access to medical cannabis emphasizes the need for an appraisal of perceptions and discuss the potential utility of some restricted medications in our client group.

We also highlight the research and audit work of some of our trainee colleagues, including an audit on risk assessments for valproate use, and an audit on antipsychotic medications for challenging behaviour at an intellectual disability service, both of them done in the greater Manchester area.

There is also a write-up call for research on people with Prader-Willi syndrome who have comorbid psychosis. Prof Tony Holland is leading this research from Cambridge, and details of how to contact him and the research team can be found in the article. There is also an opinion piece recommending improvement in the service offered to our ID clients by incorporating routine genomic/genetic testing and the suggested steps to make this routine in our services.

On the social side of things, we received a thought-provoking article on media representation of people living with LD, written by Dr Smith, one of our run-through trainees. She highlights the importance of informed representation in the media. She highlights some reasons why we all need to engage with opinion makers in society. This by extension also highlights why the newsletter is still in publication and deserving of your contributions. We also hear from a final-year medical student and her reflections on her day with a community team for learning disabilities in London. We hope she completes her medical program successfully and chooses ID psychiatry on decision day.

We were pleasantly surprised by the range and quality of submissions in response to our calls, and we are grateful to all our contributors. We hope to receive feedback on these articles and suggestions on improving the newsletter. We also hope some of you are inspired to join the editorial committee as we look forward to evolving ideas on keeping the newsletter contemporary, relevant, and something to look forward to, an addition to your routine reading list.

Finally, we thank the Editorial Committee and Kitti Kottasz, who contributed immensely to this publication in time, attention, and effort. We hope you enjoy reading through these articles as much as we enjoyed putting them together.

On a personal note, we also welcome the newest youngest members of the editorial family, Baby Proctor and Baby Rudra, to the world. We hope they have a nice and peaceful time here, in a world of peace, equity, harmony, and sustainable prosperity, a world we all collectively work towards and look forward to. Tikkun Olam

Dr. Maruf Mustapha

Key Interview

Time with the faculty financial officer – Prof. Mahesh Odiyoor

Interview by Dr Maruf Mustapha

Hi, Mahesh. Thanks for agreeing to this interview. Can you tell us more about your pathway to being a professor and consultant in intellectual disability psychiatry?

I started my medical journey in India before coming to the UK for higher training in Psychiatry. I started my training in 2002 in the Northwest region, where I have remained. I am now a consultant psychiatrist in Intellectual disabilities in Cheshire and Wirral partnership NHS foundation Trust (CWP) and provide input into 2 Assessment & Treatment units: Greenways Assessment and Treatment unit, Macclesfield and Eastway Assessment and Treatment unit, Chester. I also have strategic leadership responsibility within CWP as a Strategic Clinical Director for the ID, NDD and ABI caregroup.

My primary source of inspiration have been my parents who are both retired head teachers by background. They instilled a sense of duty as well as an aspiration to explore from the very beginning. My academic journey was later on further stimulated by my first clinical supervisor Professor Vimal Sharma. He has been a constant source of advice, support and mentoring to me. We worked on a project to develop a computerised mental health assessment tool called the Global Mental Health Assessment tool. I completed my MD degree on a project testing out the psychometric properties of the global Mental Health assessment tool. Though my primary role remains as a clinician and a clinical manager I am passionate about academic work that relates directly to patient care. The areas of research that interests me relate to population health, stratification of needs, standardised assessments and development of sustainable approaches in various health and social settings. This academic journey has led me to the role of a visiting professor at the University of Chester.

What are the current and previous roles that you've held in the faculty of intellectual disabilities?

I have been involved with college work for over ten years. I started as a regional representative for intellectual disability in the Northwest. This mainly involved supporting colleagues and improving recruitment into ID psychiatry. Following that, I was elected as an executive member of the faculty and subsequently to my current role as the faculty's finance officer in 2022. Like my Academic journey, I've done those roles as I felt I could add value and benefit to the services and people we care for.

Setting up network of Assessment and treatment services

Dr Ken Courtenay (past faculty chair) in 2021 suggested setting up a national faculty network for assessment treatment services. This was in response to the scrutiny around inpatient services for people with intellectual disabilities. The purpose of this was to offer peer support as consultants working in these units felt relatively isolated and challenged in delivering services well and also to explore current clinical practices and care standards and address variation, barriers/challenges in delivering services. areas I was requested to set this up and to chair the network in the initial days. That network has grown and now has representatives from assessment and treatment services from all the four Nations. We recently decided to open that network to all other responsible clinicians, including non-medical RCs working in those services. This has been very positive because we deliver service as an MDT, and some of our networks should also reflect that, which provides more richness and strength to the discussions we take forward.

What would you describe as some of the areas of development that you have been involved with over the past few years?

I have been involved in a number of projects that are related to enhancing delivery of care through a range of activities.

Operational delivery networks

The North West Operational Delivery Network (ODN) for Learning Disability and Autism was established in April 2017 to support the three North West Transforming Care Partnerships (TCPs) to deliver and sustain the objectives of the national Transforming Care Programme. This was a pilot pro-

gramme to test the feasibility of this model. I was appointed to the role of the clinical lead and deputy chair of the ODN and helped set up the model. This network has been quite successful in bringing together the views of the service users, carers, clinicians, commissioners and providers effectively in the region.

This network has led to development of a model for evaluating and managing children and young people with neurodevelopmental disorders and intellectual disability in the Northwest based on the THRIVE model. The network has also led on a national project to develop the concept of rehabilitation services in intellectual disability inpatient services. This has led to development of the QNLD quality network standards for rehabilitation in intellectual disability, outcomes framework as well as being included in the commissioning guidelines for inpatient care.

Supporting the development and delivery of a range of stratification tools and associated models of care

I have been involved in the development and delivery of the dynamic support database clinical support tool (DSD-CST) , which started as a CQUINN project in one of the community teams in CWP. This enabled us to create a stratification process which allowed crisis interventions to be provided to the at risk of admission population using intensive support teams. This tool and model has now been utilised across the country and has won the HSJ award for Mental health innovation of the year in 2023. This was also shortlisted for the parliamentary awards.

The concept of stratification of needs was then applied to address the significant health needs of people with intellectual Disability that has been highlighted through the LeDeR reports. This has led to the development of the Decision support tool for physical health (DST-PH) . The intention is to develop a model based on this stratification which provides intensive support to high needs individuals in primary care settings and then links with secondary and tertiary care services to coordinate and provide reasonable adjustments to meet more complex health care needs. This innovation won the HSJ highly commended learning disability initiative of the year award in 2022

Under the Transforming Care initiative introduced by NHS England, there has been a concerted drive to support people with Intellectual disability and/or Autism from inpatient settings to the community. This has led to development of alternate services such as Intensive support services to support people with complex needs in the community. Due to the additional measures that have been put in place and the efforts that are being made to prevent hospital admissions, when admission cannot be avoided, patients present with very complex needs. In the context of the changing expectations of inpatient facilities we developed an objective approach to evaluate resources needed to support people with intellectual disability in an inpatient setting. This tool is called the Universal Needs Based Resource Assessment (UNBRA). This approach has been very helpful to measure support requirements in order to ensure adequate resource allocation for safe and good quality care can be mobilised consistently.

Talking about interesting areas of development, can you tell us what CANDDID means and how did this develop?

CANDIDD stands for Center for Autism, Neurodevelomental Disorders and Intellectual Disabilities . It is the result of a collaborative effort between Professor Sujeet Jaydeokar and me with significant contributions from a multitude of people. Interestingly the idea of CANDDID was developed during a train journey to the faculty conference at Cardiff, one of those long journeys where you talk through all the issues that you never have the time to discuss in a busy clinical job. We discussed all the academic, teaching, training, research, and other activities in the Northwest region.

Success in delivering our pilot project- Better Support, Better Lives kickstarted development of new training initiatives and innovative solutions-based projects. This included developing a online training module for medical students, developing a Masters and a post Graduate certificate programme in NDD in collaboration with Chester university, developing an operational research training for frontline staff (SORT-IT programme) as well as applying and being successful in various research grants including an NIHR grant. With rapidly expanding scope of CANDDID, a number of key individuals continue to work very hard over long hours to deliver on various projects.

In all these projects, we have focused on working with people with lived experience (as patients, carers, or family). We feel that this has kept us grounded in what is important to people's real lives.

The whole ethos of CANDIDD is to bring academic principles to frontline staff, also bring academia to service users, and carers as well. To do that, we started the annual CANDDID stakeholder conference in 2022 where we brought more than 100 service users, their carers and other stakeholders in the room and asked them questions about what is it that we should be researching together. The topics that were identified as potential areas of research were summarised into key themes, and at this year's stakeholder conference, we have brought that together with clinicians, academics and service user/carer representatives to develop them into actual research protocols as we go forward.

Tell us a bit about making representations to the parliament on the Mental Health Act?

I was able to convey the concerns shared by a large number of faculty members on a number of areas of the proposed changes to the mental health act framework. These included the proposal that people with a learning disability and autistic people can only be detained under Section 3 of the MHA when a clinician identifies they have a co-occurring mental health condition warranting hospital treatment. Many people with learning disabilities who require admission to in-patient mental health units often present with a complex mix of social, environmental, physical, and mental health factors. The timescale of 28 days to assess this complex mix and decide categorically whether that person has a mental illness or not can be too short for many patients. It was highlighted that this would leave a very vulnerable group without the robust protection that the framework of the MHA provides. In addition, it was also suggested that this vulnerable group with significant health and social care needs are at a risk of being discharged into a community setting without the right to Section 117 aftercare. One of the worst outcome of the reforms could have led to more people with intellectual disabilities being incarcerated in prison.

I also shared the concerns about differentiating the definitions of mental disorder in Part 2 and Part 3 of the Mental Health Act which would have been discriminatory and potentially disadvantaged the care, people with ID would receive. I was able to challenge some of the impressions that changing the legal framework could somehow reduce the need for in-patient service or reduce the length of stay in hospitals. There is now a pause on reforming the Mental Health Act framework, and it will be interesting to see how things progress as we go forward.

You've been actively involved in the faculty executives' s future planning for the ID faculty. Can you share snippets of what you envision as the future of the ID faculty in the next decade?

This is an important question about the future direction of our faculty. Whilst we must address immediate challenges, such as improving physical health care for people with intellectual disability, the bigger picture is the engagement with people with neurodevelopmental disorders who do not have an intellectual disability. This would include engagement with various stakeholders including our faculty members as well as the members of the neurodevelopmental special interest group (NDD SIG). The focus would be on ways we harness all the skills and strengths that we have within the college including the neurodevelopmental SIG, and the ID faculty to come together and work closer together in terms of addressing the needs of people with neurodevelopmental conditions, with or without intellectual disabilities. There will be further discussions, debates and conversations with various people about that. And I'm pretty sure that will be a lively conversation to be had over the next few years.

In the rapidly evolving world of psychiatry, we must also assess and investigate emerging interventions, including pharmacogenomics, neuromodulation and use of newer medications like psychedelics. Quite a lot of times, these interventions trickle down into intellectual disability services as an afterthought from mainline psychiatry services. There is a collective need to emphasise that some of those developments should actually be assessed and investigated in our service user group. The recent excellent college report on the role of genetic testing in mental health settings (CR237) led by Dr Jana de Villiers: Chair of the Intellectual Disability Faculty of the Royal College of Psychiatrists in Scotland, is an excellent example of where members of our college faculty can and should take leadership on these emerging frontiers in Psychiatry.

Speaking of improvements, How can we improve on this newsletter?

Having a theme that could run through a series of articles such as interviews with experts in the field psychiatry of intellectual disability from different countries and bringing their experience into the newsletter, would help shed light on some of the good practices in other countries.

Most importantly, the newsletter needs to be relevant for people to take on board things that it publishes. Though it's not a peer-reviewed journal, it can have a wealth of information being shared in lighter prose, making it enjoyable.

It's been fantastic speaking with you and really grateful for your time. Is there anything you want to say to sign off any AOB's as it were?

It's been fun doing this and given me an opportunity to reflect. I would like to thank all my wonderful colleagues without whom none of this would have happened. Also a special thanks to my wife who is my polestar in all matters that really matter. I wish you and all the editorial board all the success in future endeavours.

Thanks

From the desk of the National Trainee Representatives

Dr David Anderson, ST6 Intellectual Disability Psychiatry

Dr Abigail Swift, ST5 Intellectual Disability Psychiatry

Another year has passed, and Jai and Sonya have handed on the trainee representative baton to myself and Abigail. They both worked passionately and, made great progress on helping scope the problem and support trainees with getting enough inpatient experience. A comprehensive list of possible inpatient placements that trainees can seek out or consider doing during their special interest time should be available on the faculty website very soon. Of course, using special interest time to meet inpatient competencies is far from ideal, but with the impact of Transforming Care, there continue to be fewer inpatient units such that some deaneries now have none.

It was lovely to meet a great number of new, and many existing trainees at the "Meet The Chair" event that was hosted by myself, Jai and Inder in August. Jai and I also caught up with the regional representatives in October. There continue to be concerns about the implementation of the new curriculum, especially that many trainees (me included) found the PSPDP system hard to use. As you will all be aware the system was updated again in August 2023, after the initial role out in August 2022. From my experience, and trainees that I have spoken to, the latest updates are very positive with less form filling and it being very quick to create a PSPDP for each of the HLO you are going to meet in your placement. Trainees will of course remember that after the initial confusion, activities and assessments can be mapped directly to the curriculum, so a PSPDP don't have to be created just for the sake of mapping one item. Feedback from trainees and Training Program Directors (TPD) is that everyone continues to find their feet with the new curriculum and portfolio updates, so the advice is always to speak to your supervisor and TPD to understand what the local expectations and processes are so that you don't have surprises when it comes to ARCP. The Royal College curriculum FAQ page is always a good place to start if needed: Curricula FAQs | Royal College of Psychiatrists (rcpsych.ac.uk)

It was nice to see some of you at the Faculty Conference in Leeds this November and hopefully many of you will be attending the trainee organised conference in Glasgow. Please save the date for the 26th April 2024 for the spring ID Faculty Conference that will be in London but delivered via a hybrid model. There are various projects going on in the Faculty

These can be a great experience and help meet some of your leadership competencies. Jai and Sonya were actively involved in the Recruitment Group that has seen positive progress across several regions. For example, my local Northern Deanery scheme is full for the first time in many years. I'm currently involved in a project to update the patient information section of the ID Faculty website and we are exploring how creating high quality information resources for parents and their carers that could be used across the country. Attending the meetings, many of them virtual, can be a great way of seeing how the college functions and interacts with the wider socio-political system. For those of you interested in an even deeper dive, I couldn't encourage you more to consider applying to be a trainee representative of the faculty when mine and Abbie's terms are up in May 2024 – advertisements for this will likely start in February. I would reflect that it has given me a great insight into how the Royal College functions and how as an individual you can become to get involved in policy change and advocating for our vulnerable patients on a national, and international scale! If anyone wants to find out more then please don't hesitate to get in touch with either of us.

ID Exec Updates

From the desk of the ID Specialty Advisory Committee

Learning Disability Run-Through Evaluation – a summary of the first year of the LD Run-Through Pilot.

Dr Mary Barrett-Consultant Psychiatrist for Adults with Learning Disabilities, East Midlands Region Training Programme Director for Psychiatry of Learning Disability and Chair, Intellectual Disability Specialty Advisory Com-mittee

The Learning Disability (LD) run-through training pilot programme is an innovative exercise in creating, piloting and evaluating a dedicated training pathway. The project was a

coordinated effort between RCPsych, NHSE and the GMC to see if a run-through programme offered in LD might contribute to raising the profile of LD training and help in improving the recruitment into LD training. We are grateful for the hard work, collaboration, and cooperation we received from colleagues within the College, NHSE, National Recruitment and Heads of School group. Most importantly, we thank our trainee colleagues, their supervisors, mentors and TPDs who are part of this innovative and exciting project, and who have managed training in this new pathway despite the difficulties posed by the pandemic.

This report highlights the key findings from the first evaluation of the inaugural cohort which consisted of 8 trainees. The trainees took up their ST1 posts (Equivalent to CT1) in August 2023, so have just finished their first year of training. The report highlights the strengths and issues encountered in carrying out an innovative training pilot in 'real-life' circumstances.

The programme

Trainees entering LD run-through training follow the 'standard track' completed by all core trainees. Alongside this, the Run-Through training offer supports the trainee to achieve their CCT in LD as follows:

A guaranteed 6-month post in Learning Disability Psychiatry as part of their CT rotation

Subject to satisfactory completion of CT training including passing MRCPsych within Core Training, the trainee moves into an ST LD training number in the same NHSE area without having to go back through national recruitment.

Provision of an LD ST 'buddy' from within the same NHSE area to support and mentor them during their core training.

A free place at RCPsych Annual Faculty of Intellectual Disability Meeting held in the Autumn.

A once per year free training / networking day hosted at the Royal College by the Faculty of Intellectual Disability.

The elements of the 'buddy' provision, training/networking days and attendance at the Faculty Meeting seek to engage the trainees with each other, the LD Faculty and RCPsych from the start of their training, to help create both an individual and a group identity, and to aid retention in training.

Evaluation of the first year

Six of the eleven NHSE areas agreed to participate in the first year of the pilot, as follows:

Four of the eight trainees responded to the feedback survey request; key findings were as follows:

25% of respondents had not been meeting with their named clinical (psychiatric) supervisor regularly*, however **100%** of respondents had met with their educational supervisor.

100% of respondents reported meeting with their LD run-through mentor.

100% of respondents had met the required competencies for ST1.

100% of respondents received information and preparation for ST2.

50% of respondents stated they had met with other run-through trainees/attended any RCPsych events.

100% of respondents would recommend this training pathway to others.

100% of respondents had enjoyed the programme and would recommend to others.

100% of respondents were planning to continue with run-through training into ST2.

100% of respondents were planning to continue with LD training at higher level**.

There was also some interest from one participant in considering dual training in CAMHS LD, however this would require coming out of the run-through programme to apply for dual training at ST4 level.

*This statistic is likely not related directly to the run-though programme as the trainees were in ST1 and developmental posts are usually completed in ST2/3; however it is a training issue which the College will follow up in its own right.

Geographical spread the first year of the pilot NHSE Local Office	**Number of posts**
North West	2
North East	0
Yorkshire & Humber	0
West Midlands	2
East Midlands	1
East of England	0
Thames Valley	1
London	1
Wessex	0
South West	0
Kent, Surrey & Sussex	1
Total	**8**

Next steps

Further evaluations will be carried out as this cohort progress through the programme, in particular as they move through to ST4. We are mindful that only 50% of the cohort responded to this initial survey, so further work is needed to formally capture the views of the whole group. We have however met with both the run-through trainees and mentors on several occasions through the first year to gain feedback and offer advice and support, so have confidence that the above responses fairly reflect the views of the wider cohort.

Recommendations for improvement

These are drawn from both the survey and other meetings with the run-through trainees and mentors:

Increased dialogue between the College (including via induction events and sessions at Congress) and run-through trainees to provide continuity throughout training.

Increased communication between NHSE areas and trainees to improve the trainee experience.

Increased communication for ST2 preparation so trainees know what to expect and are having goal-setting conversations.

RCPsych to build on support and dialogue with mentors, particularly during their first year in the role.

Second year planning

We look forward to welcoming the new cohort of run-through trainees entering the project in 2023. Both cohorts and their mentors have been invited to the induction/ welcome day in October at the College, which will be held jointly this year with CAP, the other training programme to currently offer run-through.

Dr Mary Barrett, Immediate Past Chair, Intellectual Disability SAC

Cherie Collins, Educational Standards Manager, RCPsych

Kathryn Squire, Training Manager, RCPsych

Special Feature

Victoria, a woman without words, but with plenty to say'

By Jean Willson– Her Mother, Carer, Advocate

Here are my beautiful daughters Tara and Victoria. Both were born with disabilities, Tara with mild Spina Bifida and Victoria with Tuberous Sclerosis.

Having been thrust into the disability world and finding a great deal of social injustice, I had to become an activist.

It was in June 1970 that Victoria was born. That same year, the Education Act was introduced whereby children with a disability, for the first time, could attend school! At six months, she was diagnosed by Great Ormond Street Hospital, who told us that this was an exceedingly rare condition, could not give us a life expectancy, but if she lived, would need total support as she would be very disabled throughout her life.

At that time, there was extraordinarily little support for families like mine; no support in the home, little benefits were available, and even Royal Mencap and Islington Mencap did not offer support. So, we found our own peer support through a charity called Kith & Kids, and I helped found the Tuberous Association, which would provide information and support.

Victoria was a difficult baby, with uncontrolled fits often going into status. She could scream for hours, and resisted cuddles and comfort. She seemed to not want to be here. For over three years she was in and out of hospital, often with life-threatening seizures or infections.

As she grew, I learnt that there was truly little equity in services, especially in healthcare. Asher behaviour could challenge, for example fighting and biting, even getting a blood test could be difficult. My view was that the medical profession viewed Victoria as someone who could not 'be fixed' therefore she was not valued, so why even give her tests. Back then, there were no integrated nurseries/playgroups or even a school that would take her because of uncontrolled epilepsy and behaviour.. We did not even get a social worker until she was three.

Then Tara developed additional health problems and our social worker told us we would have to choose between our two daughters.

Can you imagine hearing this as a family? We visited a long-stay hospital which we felt was out of the question. The only place that would take her was a Cheshire home in Dorchester which was 130 miles away, and they said it was for life. She was four years old. After a year, staff and rules changed, and we were told that we needed to look for another place.

We found other parents whose children had been deported out and we formed a campaign group to bring our children home. We campaigned hard, and eventually Field End House was opened in 1978 for eight multiply disabled children on the old hospital site in Liverpool Road. Victoria was now nine. Here she blossomed and became part of our family again. Field End was the first of its kind and was seen as a model of good practice.

Having Victoria back with us, again we experienced prejudice and discrimination, so I resumed my activist role. This included challenging Mencap in their exclusion towards children and adults with profound and multiple disabilities. Eventually they listened and people like Victoria were included.

Through my work as an activist, Victoria become a role model – the face for Profound and Multiple Learning Disability children. Together, we did amazing work, always illustrating the inequalities within services. Then Mencap invited us to lead the introduction of Hospital Passports and be the face of campaigns such 'Death by Indifference and 'Changing Places' toilets. I began talking at conferences and writing about how my daughter was being marginalised. We made films and when she was well enough, attended many of these events together.

I studied, became a social worker, and led large organisations working with and for people with learning disabilities.

In 2000, because of my lived experience with Victoria, I was invited to be on the government's Task Force to implement their white paper 'Valuing People'. This was a wonderful opportunity to form powerful partnerships, including those with learning disabilities. We did go some way to help change policy and practice, and along the way, attitudes and behaviour towards people with learning disabilities and family carers. Often family carers are disabled by association and seen as problem makers; too difficult, too emotional, too challenging. But over the years, especially collaborating with officers on the Partnership Board and today – like this group, we have gradually been accepted as problem solvers and an excellent human resource.

Throughout her life, Victoria and our family had faced discrimination and prejudice. Often refused places in theatres and restaurants, people staring and not understanding her behaviour. I was part of that parent movement that helped to change the laws. So when the Equality Act was introduced in 2020, I would go on to use this law to challenge discriminatory practices and educate other parents to do so.

Victoria lived in a series of local authority-run places in Islington, but we were never happy with the support she received. So, in 1997 when she was being housed in a new place with another family, we decided she should have a home of her own, and so we set her up in a shared bungalow near Kings Cross. Victoria and Kathy had her own staff team and we became very much part of the 'team' that was supporting them. This pioneering, innovative house was unique, and proved that people with multiple disabilities and complex health need could live independently. Islington and many others followed our model of success.

Victoria lived there safely and happily for 24 years. As a woman without words, complex health conditions including epilepsy, profound learning and physical disabilities, combined with behaviour which could challenge services and people, she needed 1-1 then later 2-1 skilled staff to support her.

Eventually, she had a terrific team who cracked her body language communication, and this enabled her to live more happily, have choices and be included in her community. She was small in stature, but large in personality and her passions in life were food, music, and men. Her house was a happy place where she loved to host parties and guests galore. She just loved to be in the centre of attention, whether being at a House of Commons event, being filmed or photographed, she was in her element. In 2011, Mencap named a 20 Hotlist of inspiring PWLDs (People with Learning Disabilities), and Victoria was one of them!

However in 2011, the tumours on her kidneys increased and as neither dialysis nor transplant was viable, she slowly went

into kidney failure. She had wonderful palliative support for 3 years, and with her Circle of Friends, we were determined that she would die in her own home.

She died peacefully and with dignity, with her family present in her own home on 22 September 2013.

My passion and drive diminished when Victoria died, and I came off all the national organisations that I worked with. A year later, I retired from my government assessor role. However, I was so impressed by the team who worked with Victoria, I nominated them for the 'Best End of Life Team' award, and in 2015, we won the Linda McEnhill award.I was then invited to be the family carer advisor on the Palliative Care for Learning Disabled people, for even in death, there is no equity.

Victoria left many legacies in her life and is still doing so. The way she died in her own home is now copied by many people with learning disabilities. The National Institute for Health & Research gave a huge grant to study End of Life Care Planning with People with Learning Disabilities. Stuart from Enfield knew he was going to die, and when he found out about how Victoria died, he wanted to 'go like Victoria.' So, this study is now called the Victoria & Stuart Project.

Victoria was a remarkable woman and was my inspiration and motivation to work for others with a learning disability. What a gift to the world she was and still is.

Jean Willson

27 September 2023

Editor's note- Many thanks to Dr Niall O'Kane- Consultant Psychiatrist, Islington Learning Disabilities Partnership, for facilitating this publication.

Audit

Sodium Valproate Risk Assessment

Dr. Sherif Ibrahim, CT3, Dr. Chanel Parmar, CT2, Dr. Rupa Gupta, Consultant in Intellectual Disability Psychiatry. Greater Manchester Mental Health NHS Foundation Trust, Bolton Division, Rivington unit.

The escalating concerns about the teratogenic effects of so-dium valproate have warranted thorough evaluation and monitoring to ensure the safe prescribing of the medication

for females in the childbearing period.

Despite significant teratogenic risks, sodium valproate is still widely prescribed to women of childbearing age in many countries as a mood stabiliser for bipolar disorder and epilepsy. The UK has recently banned valproate use in women, not in a pregnancy prevention programme. [1]

In March 2018, the European Medicines Agency endorsed new measures to avoid in-utero valproate exposure. Subsequently, updated valproate regulations published by the Medicines and Healthcare Products Regulatory Agency (MHRA) [2] contraindicate the use of valproate medicines in girls or women of childbearing age unless they participate in the Pregnancy Prevention Programme. Participants must be fully informed of the risks of valproate use in pregnancy and sign an Annual Risk Acknowledgement Form.

Some individuals lack the mental capacity to make informed choices about medication; this includes some women with intellectual disabilities (ID). People with moderate to profound ID may also lack the mental capacity to consent to sexual relationships and participation in the Pregnancy Prevention Programme. Adherence to invasive contraceptives may put women in this population at unnecessary risk of physical and emotional harm and be arguably unethical. Pregnancy would raise serious safeguarding concerns for these individuals, possibly implying sexual abuse. It also needs to be appreciated that approaching discussion around this topic can be very distressing for the individual and their families. Therefore, each case must be considered individualy, following the best interest process under the 2005 Mental Capacity Act (MCA). [3]

The prevalence of epilepsy in people with ID is far higher than in the general population, and over two-thirds of this population may be treatment-resistant [4]. Valproate remains

a first-line drug for generalised seizures, and people with ID

and refractory epilepsy may be more responsive [5]. In addition, people with ID and epilepsy commonly suffer psychiatric comorbidities. Valproate is often a good choice given its additional mood-stabilising effects, thus reducing the risks associated with polypharmacy.

Given the teratogenic effect of sodium valproate and following the recommended measures for monitoring its risk, the learning disability (LD) team within Bolton started a project in 2020 to monitor the safe prescribing of the medication and ensure that we follow the Greater Manchester Mental Health NHS Foundation Trust (GMMH) standards and the national guidelines (NICE) in this regard.

The objective of the Audit

Our audit aimed to methodically assess adherence to (NICE) guidelines and the GMMH standards. We aimed to spotlight areas of potential oversight, recommend best practices, and ensure the safe prescription of sodium valproate.

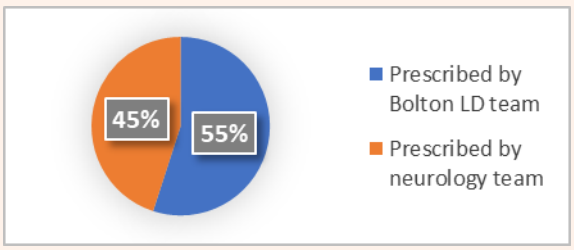
Methods

Collaborating with the ''Business Intelligence & Performance Team,'' we identified females aged 18 to 55 under the Bolton LD team. Through a systematic review of electronic records, we determined the prescription patterns of sodium valproate, the indications behind such prescriptions, and most importantly, the completion rates of essential Capacity and Annual risk assessment forms (ARAF).

Results

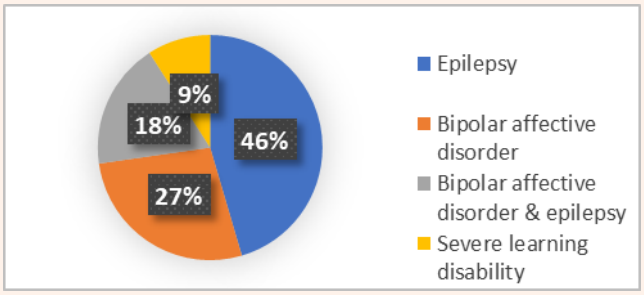
A total of 11 patients were identified under the Bolton Learning Disability team to be female of childbearing potential and prescribed Sodium Valproate. Six patients (55%) were prescribed the drug by the LD team, while the remaining five patients (45%) received their prescription from the neurology department.

Prescribers of Sodium Valproate



Considering the Reasons for Prescription, epilepsy (46%), bipolar affective disorder (27%), combined conditions (18%), and severe learning disability (9%) emerged as the indications for Sodium valproate prescription in the cohort.

Indications for starting Sodium Valpraote

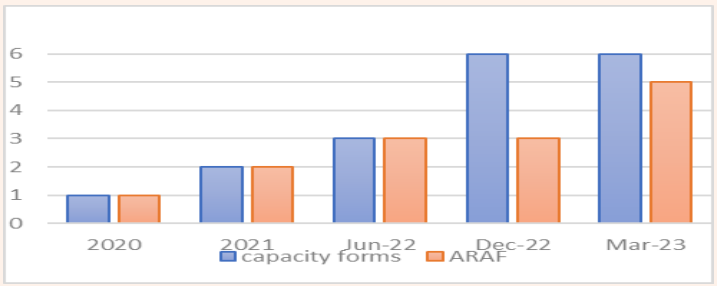


The findings showed that all 11 patients lacked the capacity to make informal decisions regarding sodium valproate prescription. This underscores the responsibility of the healthcare system to ensure the safe prescription of this drug.

The audit highlighted an optimistic trajectory in the completion of the required forms. In 2020, a mere 14% had completed forms. Encouragingly, by 2023, this figure had jumped to 83% for the ARAF and achieved 100% compliance for capacity forms.

	2020	2021	June 2022	December 2022	March 2023
numbers	7	8	7	6	6
Capacity form	1 (14%)	2(25%)	3 (42%)	6 (100%)	6 (100%)
ARAF	1 (14%)	2 (25%)	3 (42%)	3 (50 %)	5 (83%)

The proportion of capacity and Annual Risk Assessment Forms completed between 2020- 2023



Graph showing the numbers of the ARAF and Capacity Forms completed over the study period.

Challenges

Since the project started in 2020, our main obstacle has been ensuring the thorough comprehension and signing of required forms by families and caregivers for incapacitated patients. The COVID-19 pandemic introduced an unforeseen challenge. The shift to remote clinical reviews made completing physical forms significantly complicated.

Another challenge was the expired forms. Some forms, although previously completed, were discovered to be expired (older than a year). For the audit's purpose, these were treated as non-completed.

Achievements

The Bolton LD team proudly achieved a 100% completion rate for capacity forms. This consistency is attributed to the proactive approach by clinicians in filling them out.

With strategic interventions like posting the ARAF forms to patients' caregivers and organising specific sodium valproate face-to-face clinics for risk discussions, ARAF compliance saw an impressive jump from 50% to 83% in a short span.

Conclusion and Recommendations

In conclusion, the significant increase in the compliance rate for valid forms concerning the prescription of sodium valproate strongly indicates proactive dialogue and the involvement of families and caregivers. This emphasises the shared responsibility to address the risks associated with pregnancy while using sodium valproate. Furthermore, this underscores the effectiveness of our interventions, notably the distribution of forms and the strategic approach of inviting patients and caregivers to dedicated face-to-face clinics for discussing the medication. However, the unavailable forms in our electronic records as a mental health team for the rest of the patients under the team who were prescribed sodium valproate by the neurology team remain of concern. This challenge arises from communication gaps between teams and diffusion of responsibilities between the teams and primary care. This gap highlights the crucial need to ensure discussions about the medication's risk during pregnancy and the regular updating of forms. Equally important is the need to maintain the continuity of this project annually and to ensure that there are dedicated time slots for clinicians to discuss sodium valproate with patients and their families.

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Poster

Audit of the use of antipsychotic medications for challenging behaviour at an intellectual disability service in Manchester.

Dr Akinloye Akinfala (ST5, ID Psychiatry) Dr Joshua Bassey (CT2)
Dr Rahnuma Sharmin (GP Trainee)
Dr Rupa Gupta (Consultant Psychiatrist, ID Psychiatry & Audit supervisor)

Background

People with an intellectual disability (ID) have fewer coping strategies and resilience when dealing with adversity, which may manifest as challenging behaviour (1). Challenging behaviour is relatively common in people with ID especially those with severe ID (2). It has been estimated that between a quarter and a third of people with ID across hospital and community samples exhibit such behaviour (3,4) and the lifetime prevalence may be as high as 60% (3). There are concerns regarding the overuse of psychotropic medication in people with ID and the harm this may cause. Studies have shown that there is overprescribing of antipsychotics for the

management of challenging behaviour in people with ID, both in the adult and in children and young people (5). NICE recommended that antipsychotic medication should only be considered for managing challenging behaviour in people with ID where other interventions have failed or the risk to the person or others is severe, for example, because of violence, aggression, or self-injury (4). However, for those who are prescribed antipsychotics, there are NICE guidelines on how these patients should be monitored due to the side effects of these medications (4). Many patients are also prescribed these medications longer than necessary (5).

Aim

To determine the service prescribing practice against the standards set by the National Institute for Clinical Excellence (NICE) guidelines on the use of antipsychotic medications for the management of challenging behaviour in people with ID.

Method

The audit tool was developed by the investigators using the NICE guideline as a standard. The investigators carried out a review of patient electronic records and clinical letters of patients with ID on the caseload to gather information pertaining to the initiation of antipsychotics and physical health monitoring of patients prescribed antipsychotic medications for challenging behaviour. Patients with other mental health disorders such as psychosis and depression were excluded.

The audit was conducted between April and June 2023. The standards that were examined are displayed on table 1. Each standard was rated as red (0-44%), amber (45-79%) or green based on the proportion of patients who met the criteria.

Results

The sample size was 26; 61.5% were male and 76.9% were of White British ethnicity. The mean age was 34.8 years. More than half of the study population had a severe ID and were started on antipsychotics before being transferred to our services. Therefore, there were gaps in the information about the initiation of the medication, psychosocial interventions, and baseline monitoring prior to the commencement of the medications as these were not clearly stated in the referral

Conclusion

The service is doing well in terms of follow-up prescribing in conjunction with non-pharmacological support, monitoring for side effects and physical health. However, there were gaps in documentation regarding the initiation of these medications by other services, therefore this audit could not depict the actual prescribing practice of our service.

Recommendations

1. The service is to develop a checklist for future antipsychotic initiation for challenging behaviours and this would be reviewed as part of new patients' assessment for challenging behaviour.
2. It is recommended that future transfers and referrals to the service are monitored for adherence to the NICE guidelines and ensure that these are documented as part of the transfer or referral pack of the service user.
3. To conduct a re-audit of patients where the medications were initiated by service (and not externally).

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Table 1: The standard guideline for prescribing antipsychotic medication for challenging behaviours with RAG Rating.

	COMPLIANCE	
STANDARD	**ACTUAL %**	**RAG (red, amber or green) rating and reasons for inadequate rating**
Non-pharmacological methods of behavioural intervention are considered before medication.	**38.5**	**Non- compliant** Medication initiation was started by other services and some of the information about the initiation of antipsychotics was not available.
2. Medication, when initiated, is used in conjunction with non-pharmacological methods	**69.2**	**Partially compliant** Some of the referrals highlighted the input of LD nurses and other MDT involvement.
3. Information about medication given before initiation.	**23.1**	**Non- compliant** Medication initiation was started by other services and some of the information about the initiation of antipsychotics was not available.
4. Medication was initiated and monitored by a specialist.	**65.4**	**Partially compliant** Some of the information about the initiation of antipsychotics was not available.
5. Started with a low dose and use the minimum effective dose needed.	**61.5**	**Partially compliant** Some of the information about the initiation of antipsychotics was not available.
6. Only prescribe a single drug.	**76.9**	**Partially compliant** Some of the information about the initiation of antipsychotics was not available.
7. Targeted behaviours stated.	**84.6**	**Compliant**
8. Baseline monitoring is completed when initiating medication.	**38.5**	**Non- compliant** Medication initiation was started by other services and some of the information about the initiation of antipsychotics was not available.
9. Review the effectiveness and any side effects of the medication within 6 weeks of starting.	**42.3**	**Non- compliant** Medication initiation was started by other services and some of the information about the initiation of antipsychotics was not available.
10. Continue to monitor for side effects and record the extent of the response, and how the behavior has changed.	**76.9**	**Partially compliant** Some of the information about the follow-up after the initiation of antipsychotics was not available.
11. MDT review at least every 6 months.	**61.5**	**Partially compliant** Some of the information about the follow-up after the initiation of antipsychotics was not available.
12. Ensure Annual physical health monitoring.	**92.3**	**Compliant** Access to GP records was possible.
13. Shared care protocol is given to primary care.	**42.3**	**Non- compliant** The GP had been prescribing the medication before the transfer of care to our service, so there was no requirement for shared care protocol in several of the cases.

Special Feature

Medical Cannabis: from a medical patient's perspective

Dr Laura Korb- consultant in Intellectual disabilities psychiatry and medical cannabis advocate.

Hello Dr Korb. Can you please tell us a bit about yourself

I am a Consultant Psychiatrist in the Psychiatry in Intellectual Disabilities and I work in Haringey, North London. I attended medical school in Birmingham, intercalating in psychological medicine. I worked in Trent for my foundation years, before moving to London for my core and higher training. I completed my training in 2020 and joined the Haringey team after acting up in the post. I have always been interested in neurodivergence. As a higher trainee, I was the deputy editor of the RCPsych College report on ADHD in Intellectual disa-bilities. In my homelife, I have a son, who is nearly 8, and two Devon Rex cats.

Why Intellectual disabilities psychiatry

As a core trainee I loved my job in ID psychiatry. It was a split role between a ward and community. I enjoyed the variability of the role and was interested in the diagnostic challenges in the patient population. As a community consultant, I can go from managing acute mental illness, to optimising medica-tion in a person with severe ID, to diagnosing and managing a person with dementia. I also enjoy working closely with other disciplines.

What is the role of advocacy for a consultant in ID

I think there is a duty for us to speak up on behalf of our patients. We need to ensure that in our medical opinion, the person is getting access to treatment that they require, even if this on some occasions means opposing the views of the family or peers.

What is it like living with TLE, med school, work, social life etc?

I was diagnosed with temporal lobe epilepsy in my mid-30s, and I was fortunate to have completed my training prior to diagnosis. I had to stop from doing on calls, which in my opinion, would have been detrimental to my training at an earlier stage as I valued what I learnt during out of hours experience. The biggest challenge for me was getting used to not driving, as this meant I must go on two buses and a train to and from my work location and travel around the

borough on buses. I am grateful that the London transport system is fantastic, but due to the medication that I have been prescribed and the illness itself, my levels of energy are low, and I initially found travelling to be exhausting. I am much better now but when I was having regular seizures, I had to work mainly from home and I went to bed regularly at 7pm, leaving me little time to do anything beyond work. When I was having regular seizures, I made sure to be transparent about any difficulties I might be having. I kept in contact with occupational health and my line manager, as well as the MDT.

Can you tell us a bit more about your experience with medical cannabis, from a patient's perspective

I initially was started on lamotrigine. Sadly, I came out in a rash, that later became ulcers and blisters. Due to it being on a bank holiday weekend and having junior doctors who were relatively new to their roles, I had multiple trips to hospital. Eventually I got to see a dermatologist and was diagnosed with Steven Johnsons' syndrome (thankfully a mild version, but the maximum dose I was prescribed was only 25mg a day…a reminder why we need to titrate this medication so slowly). I was prescribed steroids and then started on Keppra. When I got to higher doses of Keppra, I was still having 3 -4 seizures a month (clustered around one or two weeks), and I felt low in mood, at one point feeling like worth was not worth living. I had never experienced depression or felt this way before. I was told to take Clobazam to try to stop the seizures, but this entirely knocked me out. It was then that I decided I would rather have monthly seizures than continue Keppra at a higher dose/clobazam PRN. I started looking into alternatives. I had already researched medical cannabis as an option for my patients with ID and ASD.

I was seen by a private medical cannabis clinic and started on high dose CBD oil (150mg a day). After two weeks, I stopped having seizures. I began to reduce my Keppra and got to the minimal effective dose. I would have liked to increase my CBD further, but the evidence is that as a single agent, the dose needs to be much higher, and the expense is prohibitive. I haven't had a seizure since mid Feb 2023, and I feel like a different person. In summer I went swimming without anxiety. I can travel without having to fear that I will have a seizure and end up falling onto the train track. I don't have the fear of having a focal seizure in the middle of seeing a patient. I no longer have the concern about not remembering my son's name when he asked me in the post ictal phase (which he often did!). Simply put, starting medical cannabis has been life changing.

That's fantastic news. Happy to hear you've made such a great recovery. What were the alternatives?

When I was reviewed by neurology, they advised for me to use clobazam for two weeks a month, as I had been diagnosed with catamenial epilepsy. On this medication I was not able to function, even when using at small doses once a day, and I ended up having a focal seizure the day after stopping the clobazam, so I didn't feel that it was a workable solution.

Since being seizure free, I have attended a follow up with the neurologist, who said that I could not be prescribed the NHS version of the oil I had been taking (Epidiolex). Cenobamate was also offered as an option but I made the decision not to go ahead with this choice, based on the evidence I read and my personal circumstances. Given I was already seizure free, I did not want to risk relapse or the side effects, which include heavy sedation. This is a patented and expensive new medication that would be extremely expensive for the NHS.

What forms of CBD are available on and off NHS prescription

On the NHS there are very few options. Epidiolex is pure CBD in a liquid form. It is licenced in seizures in children (aged two or older) with two rare forms of epilepsy, Lennox-Gastaut Syndrome and Dravet syndrome, in conjunction with clobazam, and as adjunctive therapy of seizures associated with tuberous sclerosis complex. There are some other forms available of cannabis based medicinal products including Sativex, which is an oromucosal spray with a combination of THC and CBD, which is licensed in multiple sclerosis associated with spasticity unresponsive to other treatments. Finally, Nabilone is a synthetic cannabinoid mimicking the effect of THC, which is licensed for chemotherapy induced nausea and vomiting unresponsive to conventional anti-emetics.

However, these licensed products can be given for 'off-label'

and 'non-formulary' usage if agreed by the trust via their local processes. This is different depending on the trust. I am due to go to the Trust's Drug and Therapeutics committee meeting to present my application for Sativex to be added to the formulary as 'an alternative medication option with a low side effect profile in a vulnerable group of individuals that often get left on medication that is ineffective and not well tolerated.'

In the private sector there are many more options. Full spectrum oils/dried flower to be vaped (smoking is illegal even if prescribed) and pastilles that are prescribed as per protocol of the prescribing clinic. These products will either have CBD/THC or a combination of both. They are used off-label and off-licence in specific clinics for a range of conditions for which there is emerging evidence and where conventional treatment has been tried. Medical cannabis currently can only be initiated by a specialist in the field being treated. For example, a neurologist must initiate for neurological conditions. This is how I was prescribed medical cannabis. As a psychiatrist both in the NHS and my private work as a consultant, I only prescribe for mental health conditions for individuals that fulfil the eligibility criteria. Suffice to say, the clinics have to have undergone the requisite registration and approvals via CQC etc.

Medicalization, legalization, or decriminalization? What are the risk issues involved?

There is a concern regarding the potential for dependence and withdrawal syndromes. However, the evidence suggests that the risk of recreational cannabis dependence occurs more commonly in those using high THC strains with daily heavy use from an early age.

There is a known risk of psychosis with THC use, but as a patient (and an expert), I have explored the evidence and understand the risk to be low when cannabis is the only drug used. Other people will come to different conclusions based on the evidence, and there is no doubt that further evidence/research is required in the field.

There is evidence that psychosis is more likely with a lower age of onset, high use and with high THC products. Psychosis is not linked to high dose CBD usage. There is also the 'chicken and egg' argument, as often people with prodromal psychosis, would feel anxious and may want to 'self-medicate' with cannabis-based products.

Any analogies/similarities or differences with prescribed stimulants for ADHD?

There are many similarities. As with cannabis, stimulants have an associated risk of inducing psychosis and yet interestingly they are not considered the same way from the public or the profession. Stimulants have been used as street drugs, but there certainly seems to be less stigma associated with ADHD medication. Although ADHD medications are controlled drugs, there are also less restrictions for prescribing than with cannabis-based products, and these medications are relatively easily available on the NHS.

My view is that cannabis should be seen similarly to ADHD medication when it comes to the law. Given the aim is to reduce recreational use, reduce risks but retain the therapeutic benefits, I would argue that cannabis-based products continue to be prescribed by clinicians and made easier to access on the NHS.

I recently participated in a clinical scenario examination and one of the vignettes spoke about a young man using cannabis recreationally prior to his admission for a psychotic episode. There are risks of becoming psychotic when prescribed stimulants, high dose steroids or any number of medications, but cautious prescribing and considering risks vs benefits is part of the job of a prescribing clinician.

Is there any role for undergraduate medical education moving forward

I believe there is a huge role across all specialities. From what I have seen, in mental health, pain medicine and neurology there is a definite need to question the status quo. Today's medical students need to understand that there is so much we don't know and to not just accept 'good enough' treatment when they can be alternatives.

Any interesting 'treatment response' experiences to share?

In my NHS practice I started a 30-year-old man with severe LD, autism, epilepsy, and ADHD on sativex. He struggled with symptoms of insomnia, aggression, tearing clothes, grabbing others etc. He had a poor quality of life as his family were staying away from him and respite/day centre were concerned about their ability to support him. He had been prescribed many different types of medication since childhood including olanzapine, pregabalin, aripiprazole, fluoxetine, atomoxetine, lisdexamfetamine, methylphenidate, sodium valproate, risperidone, carbamazepine. I applied for him to start on Sativex, which was supported by my trust. He reported as being happier, settled, sleeping better, initiating activities on his own, and no incidents of aggression either at home or at the day centre. Since presenting this case, I have been asked to present my formulary submission to my trust's drug and therapeutic group meeting. If approved, I will aim to start appropriate patients on Sativex. With consent by the patient or their family, I will aim to collect data on their response.

I had another patient who was smoking cannabis. She has a

mild learning disability and severe PTSD, with a psychotic episode after being sexually assaulted. She is extremely vulnerable in the community, especially when buying street cannabis. However, she continued to buy cannabis as she said it was the only medication that stopped her nightmares and flashbacks. Without smoking cannabis, she experienced day-night reversal because she was too scared to sleep at night. I advised that she went to a medical cannabis clinic to have an objective view on whether she would be suitable for prescribed cannabis, as I was aware that my trust would not agree to prescribe dry flower as this is not a licensed product. She was found eligible for medical cannabis and has been vaping the product since. Her family are shocked by the positive response, and she is now planning on going to beauty college as she is sleeping at night, and she is awake during the day. Her response has been excellent, and her risks have been reduced when compared to buying street cannabis. However, she is struggling with the costs from the private prescription.

What are the common illnesses in PLWID that are potentially manageable with medical cannabinoids

People that are unresponsive or intolerant to first line treatment for the following conditions:

PTSD, Anxiety, ADHD irritability (secondary to stimulant prescription or as a replacement if intolerant to first line options)

ASD – sensory overload, meltdowns, Post ictal aggression (Due to improved seizure control)

Any paper or journal recommendations? Are you involved in any research in this burgeoning field, especially as it concerns PLWID

I have had a paper accepted for publication on the topic of ID and medical cannabis: The potential for medicinal cannabis to help manage challenging behaviour in people with intellectual disability: A perspective review (DOI: 10.1177/02698811231209192/ ID: JOP-2023-5319.R1).

This will be published soon in the journal of psychopharmacology.
I have contributed to a paper on anxiety and cannabis use, related to the medical cannabis registry that is held by the clinic that I work in for 4 hours weekly.

Thanks very much for sharing your time and your invaluable experience. On a final note, do you have any book, podcast or movie recommendations?

I would recommend reading the book cannabis is medicine by Dr Bonni Goldstein. There a recent podcast on BBCiplayer called Behind the Stories, Cannabis: Prescription Potluck? This was a snapshot into some of the issues people have receiving the cannabis-based medication that they require.

References-

1. **The potential for medicinal cannabis to help manage challenging behaviour in people with intellectual disability: A perspective review (DOI: 10.1177/02698811231209192/ ID: JOP-2023-5319.R1).**

Conflict of interest statement-

Dr Laura Korb works privately half a day a week for Sapphire Clinics https://www.sapphireclinics.com/ which is a medicinal cannabis prescribing private clinic. I also run a cannabinoid peer group in my Trust. I have contributed to the Volteface-led report for the All-Party Parliamentary Group exploring the need for appropriate and indication-specific prescribing of cannabis medications in the UK.

Editors note

Experiences and opinions voiced in this article are of the authors, and should not be taken as an official position of the Royal College, neither should it be taken as medical advice. If you have any questions or comments about this article, you can email it to the editor **newsletter.psychid@gmail.com**

Research

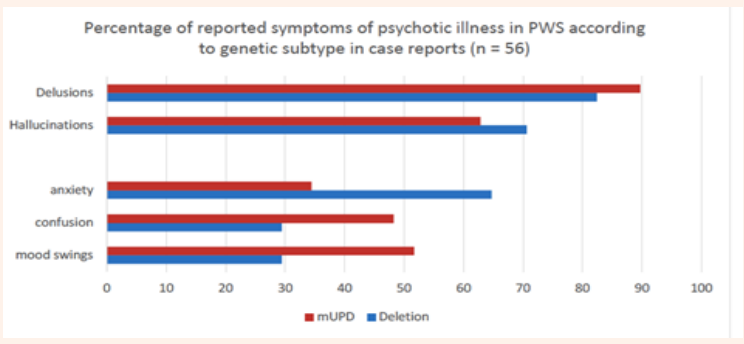
Affective psychosis in children and adults with Prader Willi syndrome (PWS)-Investigating mechanisms to in-form treatment

Dr Prof. Tony Holland

An important advance in the field of the psychiatry of intel-lectual disabilities has been the recognition that particular neurodevelopmental conditions, usually of genetic origin and associated with having an intellectual disability (ID), may have a specific neuropsychiatric or behavioural phenotype. These associations can inform clinical practice, guide investigation of the underlying causal mechanisms that results in the syn-drome-specific neuropsychiatric phenotype, and ultimately may result in the development of effective interventions.

In this article I consider one such very striking example - the high risk of developing an affective psychosis in the teenage years or in early adult life in people with Prader-Willi Syn-drome (PWS). This genetically determined neurodevelop-mental syndrome is well known for being associated with hyperphagia and the consequent risk of life-threatening obe-sity if access to food is not managed (Bellis et al 2021). The risk of psychosis is perhaps less well known. What is striking is that this risk is particularly high in those people with the rarer genetic sub-type of PWS, referred to as a chromosome 15 maternal uniparental disomy (mUPD) compared with the more common cause of PWS, a chromosome 15 deletion at 15q11-13 of paternal origin (Boer et al 2002, Soni et al 2008). This observation of differential rates of psychosis depending on the genetic sub-type suggests that it isn't the PWS geno-type that is giving rise to this risk but specifically the geno-type that is unique to having a mUPD (Aman et al 2018).

In a recent systematic clinical review of the symptoms of psy-chosis in people with PWS Aman et al (submitted) described the characteristics of the psychosis. These were phenomeno-logically like those of cycloid psychosis having a strong affec-tive component, often of sudden onset, some evidence of confusion, and the presence of abnormal mental beliefs and experiences. This is shown in Figure 1 below



As yet there are no trials of treatment for the psychosis. Once the diagnosis is made usually anti-psychotic medications are tried (avoiding those most prone to increase appetite) some-times in combination with an antidepressant at a low dose, or mood stabilizing medication. One small follow-up study indi-cated that the outcome is in general positive (Larson et al 2013). The challenge, in terms of choosing the most appropri-ate treatment or developing new treatments, for psychosis in people with PWS, is that the neural pathways and neurotrans-mitter systems that are affected and which result in psychosis are unknown.

Based on the predictive coding model of psychosis and on the assumption that GABA/glutamate imbalance may be core to our understanding of psychotic illness we have been un-dertaking a study comparing people with the different genet-ic sub-types of PWS aged 12 years or older (in the age at risk for psychosis). The study includes clinical and cognitive as-sessments, and investigations using electroencephalography, Magnetic Resonance Spectroscopy (MRS) and Magnetic Res-onance Imaging (MRI). Prior to the pandemic we were able to show that these methods were feasible and also acceptable to people with PWS. Figure 2 illustrates the type of spectrum that can be obtained using MRS from the area of the brain studied and Figure 3 illustrates how comparisons between genetic sub-type of PWS – deletion with a low risk for psy-chosis and mUPD with a high risk of psychosis – might be able to identify differences in chemical signatures, which in turn may be an indication of underlying biological risk of psy-chotic illness.

Fig. 2

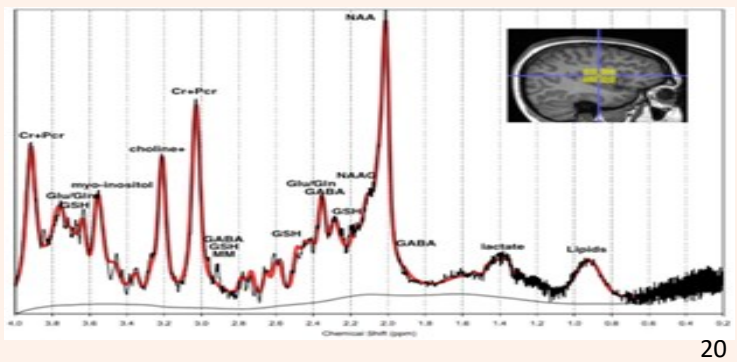
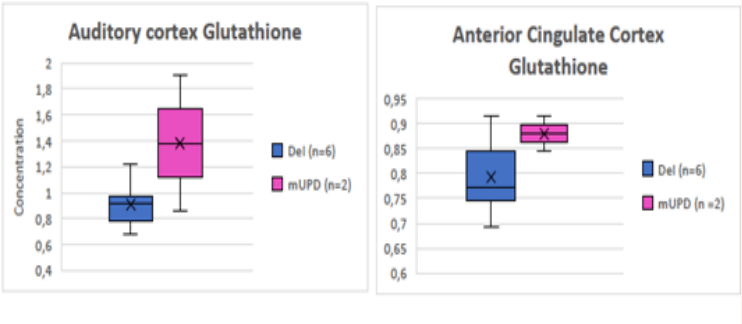


Fig.3



We are now restarting the study and would be grateful for your help identifying people with PWS aged 12 years or older, with or without a history of mental illness and of both main genetic sub-types. We have ethical approval for the continuation of the study. This research is in partnership with Professor Paul Fletcher at the University of Cambridge, who is an expert on psychosis in the general population. Lucie Aman undertook the early work for her PhD. Suzannah Lester is leading on the MRS project and Lucie Aman is joining us again to complete the EEG component of the research. This continuation of the study is being funded by the Foundation for Prader-Willi Research (FPWR).

If someone with PWS, their family, professional carer, or a clinician would like to know more about the study please contact us directly and also pass on our emails to others (see below). These studies are a challenge and are only possible with the support of people with the syndrome and with the encouragement of their families and clinicians. Thank you for your help.

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Reflections

Psychiatry Elective at a community learning disability service

Eva A Koffi, Final year medical student

For the first month of my fourth year medical elective, I got the opportunity to travel to London to join the psychiatry team at the Islington Learning Disability Partnership (ILDP). After doing a general adult psychiatry placement in my third year, I developed an interest and wanted to use my elective block to explore the specialty further. We don't get a lot of teaching about learning disabilities in medical school, so I was keen to use the experience to develop my knowledge and communication skills.

I thoroughly enjoyed my time there, and was exposed to a complex multidisciplinary team, who support approximately 500 service users. I shadowed consultations, attended meetings and carried out mental state examinations during my placement.

My main aim for the placement at ILDP was to gain confidence in communicating with people with learning disabilities and communication difficulties. This is important to me as 2% of the UK population has a learning disability (1), and difficulties in communication with healthcare staff is a widely known barrier to accessing healthcare for people with learning disabilities (2). In order to achieve this aim, I observed health and social care professionals such as social workers and learning disability nurses during their consultations, attended trust-wide lectures and teaching, and took part in a Makaton session with a speech and language therapy assistant.

The Makaton session was very informative, and from the hour long session I was able to sign simple words and phrases such as 'hello' and 'I am a medical student'. The speech and language therapist informed me of the significance of Makaton in the LD community, and how even signing one or two words in a conversation can make a patient feel respected and slightly more at ease. I did actually try and sign 'hello' at one of the home visits I went on!

I spent a lot of time in clinics, and was introduced to lots of lovely patients, many of whom had complex psychiatric needs. I met a patient , who had a mild/moderate learning disability and borderline personality disorder. He came into clinic for a review, and was accompanied by an advocate from a local charity. as well as a friend. His social worker was also present.

The appointment had a challenging start, as the patient had arrived with a rope tied tightly around his neck and was making strained faces and bulging out his eyes. He appeared very distressed and was teary. He then began to hyperventilate and cry. I observed the psychiatrist help to de-escalate his behaviour over the course of around 5 minutes, by providing reassurance and helping him control his breathing. He then removed the rope and was able to begin his appointment, but appeared to still be heightened. He pointed at me and asked 'who is she?'. This made me feel alarmed, as this was a highly tense situation, and I didn't want to distress the service user further. I realised I should have introduced myself before I entered the consultation room, as this would have allowed the service user to have consented to my observation of the appointment. I then introduced myself, and explained in simple language who I was and why I was there. I then asked if I was able to stay, and why I wanted to. He instantly looked relieved from the simple explanation, and welcomed me to the appointment.

This was a key learning experience that occurred at the start of elective, but provided a learning outcome that I used for the entirety of the 8 weeks, and will continue to use in clinical practice. It has made me ensure that I personally introduce myself to patients before joining observational clinics and not rely on the doctor to do this for me. This is in line with GMC guidance on communicating with patients with learning disabilities (3), and I feel abiding by this will have a positive impact on my clinical practice.

Another take home message from my time at ILDP, was the importance of clarity when speaking to patients. This applies to all patients, but with LD patients language has to be particularly simple and easy to understand. Visual aids such as easy read leaflets may also be helpful, as well as actively checking whether the patient has understood what you have said to them. I now make sure to simplify my language when speaking to LD patients on all clinical placements.

Overall, my experience at ILDP was a very positive one. I worked with a fantastic team, and learned a lot about learning disabilities and how to better communicate with the LD population. This experience really sparked an interest for me, and I then went on to do a Student Selected Component placement on a learning disability forensic psychiatry ward in the summer, which I really enjoyed. I used a lot of the new skills I learned from ILDP on this placement, and look forward to using them to develop my practice in the future.

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Article

Representation of Intellectual disability (ID) in the BBC show 'Call the Midwife': high-lighting issues in the care of people with intellectual disabilities (PWID).

Dr Emma Poynton-Smith, ST1

In this brief article, I reflect on the representation of intellectual disabilities (ID) in the TV show Call the Midwife, noting some ongoing issues identified by the show in caring for people with ID (PWID).

Call the Midwife

Call the Midwife' a BBC show which follows midwives in Poplar (an impoverished area of London) in the 1950s, has had several episodes focusing on people with disabilities, and one of their storylines in 2014 featuring a pregnant couple with Down syndrome and cerebral palsy was welcomed by disability charities (https://www.independent.co.uk/voices/comment/call-the-midwife-is-making-bold-steps-in-portraying-disability-9136655.html).

Since then, more recent series have featured a main character with Down syndrome, Reggie, who actor Daniel Laurie plays. Through his role, Call the Midwife has explored themes related to PWID, such as independent living: Reggie spends much of his time living in a care community for young adults with various disabilities. Reggie's character also shows the *capabilities* of PWID, as he works in a shop when he visits Poplar and has been instrumental in helping and showing kindness to various characters in the last few series.

However, Reggie is often underestimated, with characters feeling the need to hide elements of the truth from him to protect him, for example, information about his mother's death.

Consequently, Reggie, in a recent series, was unwilling to share his health issues (low mood and fatigue, which were eventually linked to hypothyroidism), as with the information he had been given about his mother's death previously, he concluded he was dying and wanted to protect others. He could have received appropriate care sooner had he not been misinformed about his mother's death.

Links to real-life

Reggie's character is a fictional example based on a some-

what idealised view of the past. In reality, at this time, the medical model was prevalent, and the asylum movement was in full swing (https://onlinelibrary.wiley.com/doi/full/10.1111/bld.12461?casa_token=aYc_Qb9D5UAAAAAA%ACEjtBem8lIrRrwSQER22whnRSlQr_PkMKeXtSxy6qhil7iHzGnMaMwMnTCicr7jMqEsB5SvCIYg).

However, accounts from the time do suggest that informal family support was also paramount

(https://academic.oup.com/shm/article-abstract/19/3/545/2953569?redirectedFrom=fulltext).

Nevertheless, Reggie's case demonstrates some ongoing issues which continue to affect PWID, especially care arrangements and the problems associated with PWID being underestimated, including respect, capacity, and 'compassionate deception' (trying to help or protect people by lying to them or avoiding the truth).

Care arrangements

The current care situation for PWID in the UK remains complicated, with day-to-day care provided (where necessary) through a combination of family support and paid carers. Following the abolition of asylums in the 1990s, a period of more focus on patient-centred care and legal commitment to inclusivity followed. At present, there are various types of supported living/residential care. However, they still face practical issues: given that over 2% of UK adults are estimated to have ID (https://www.mencap.org.uk/learning-disability-explained/research-and-statistics/how-common-learning-disability), care for those who need it is a significant undertaking, with current issues such as poor support for staff and high turnover rates.

Respect, capacity, and compassionate deception

- As shown in Call the Midwife, PWID is often underestimated and not given the respect that everyone deserves: a 2019 BMJ Opinion piece by authors with ID https://blogs.bmj.com/bmj/2019/07/02/whorlton-hall-panorama-should-alert-us-to-systemic-neglect/ identified that this lack of respect had resulted in a systemic failure to protect and empower PWID, resulting in several cases of institutional abuse.

In healthcare especially, it is essential that PWID are supported to make their own decisions where possible: this is a central tenet of person-centred care, as well as in upholding human rights. This became especially relevant during the first waves of the COVID-19 pandemic when PWID were vulnerable and struggled to access healthcare, with high mortality rates and concerns raised regarding discrimination and human rights. Informed decision-making cannot be supported in situations where healthcare professionals make assumptions about capacity or when the patient is misinformed due to compassionate deception in terms of either omission of information or misleading information being given. Reggie's health issues in Call the Midwife demonstrate that compassionate deception can have direct negative impacts on health. The focus must, therefore, be on conveying infor-

mation in the best possible way to support understanding for all patients and assessing capacity for all decisions.

Conclusion

Reggie's character in Call the Midwife is complex. It demonstrates several considerations regarding PWID's health, which are ongoing today, including the dilemma of care arrangements and PWID's ability to make decisions, as well as how a lack of respect or information-giving can hinder this.

Summary

- 'Call the Midwife' has a main character with Down Syndrome (Reggie).
- The problems he faces in the show can make us think about issues to do with PWID's care in real life.
- It also shows what can happen when PWID are not treated with respect and given the necessary information.

Article

Let's decode LD with genomic Testing

By Dr Ambreen Asma

Mental health services and genomic medicine: NTGMSA local transformation project - Embedding genomic testing in dementia and intellectual disability services

The NHS has embraced recent research in human genomics to better diagnose and personalise treatment of increasingly diverse conditions including cancer, cystic fibrosis and other rare diseases. Up to 40% of people with Learning Disability are estimated to have a variation in their genetic make-up that contributes to their condition and can provide valuable information on current and future management of specific health conditions (dementia, epilepsy, mental ill health) amd support personalised health care planning. Genomic investi-gation is available for people with intellectual disability and people with a suspected inherited form of dementia via the National Genomic Test Directory. The proportion of people with intellectual disability for whom a genomic diagnosis can be made has dramatically increased over the last 10 years or so with the clinical application of microarray and next generation sequencing technologies. Unfortunately, the majority of adults in contact with intellectual disability services will not have had the comprehensive genomic investigation. It is of paramount importance that this gap is filled, as in addition to contributing to explaining a person's intellectual

mental health and physical health screening and monitoring. Furthermore, some genomic diagnoses have implication for drug prescription.

Our team has been working with London Genomics Hub to re-launch the offer of Genetics Testing of people with learning disabilities to ascertain a possible genetic basis for their complex presentation.

The Aim/Objective of this project is to increase the understanding of genomics and improve the uptake of genetic testing in LD services for people with Learning Disabilities and their families, through

Education resource development

1. Identifying competencies required to effectively conduct genetic testing.
2. Identifying and developing resources to allow clinicians to gain relevant competencies.
3. Building on existing resources where appropriate and development of new resources.

Pathway Development

1. Identifying steps needed for safe and effective genetic testing in people with an intellectual disability.
2. Building in existing processes were appropriate, ensuring equitable access to genomic testing to reduce disparity in health outcomes.

Facilitating improved understanding of genetic conditions in people with an intellectual disability

1. Establishing a multidisciplinary team to discuss difficult cases, encouraging publication and contribution to the network outlined below which will allow harmonisation of reporting and data collection. This will include clinical geneticists, clinical scientists and intellectual disability psychiatrists.
2. Improve the understanding of differences in prevalence of genetic conditions by area.

Looking to the future and facilitating research

1. Establish a network of scientists, geneticists and psychiatrists specialising in intellectual disability to enhance diagnosis and management of genetic conditions.

2. To improve diagnosis and knowledge of intellectual disability related syndromes.

Troubleshooting the Pathway
1. Feedback from services using the pathway
2. Identify Genomics Champions to visit GOS Hub
3. Practicalities of blood/saliva testing
4. Manage expectations re waiting for results and understanding them

Networking across GMSA
1) Attendance at Nursing and Midwifery meetings
2) Meeting with GMSA Leads
3) Poster sessions/ppt presentations at discipline specific (nursing/psychology or AHP) LD learning events
4) Collate national research around genetic testing in developmental delay and learning disability

Presentation of QI Project findings and Sustainability model
1. Link to Dementia Service Genomics QI Project
2. Define role of Genomics Champions in sustainability
3. Alternative funding options for Champions
4. Research future funding of genomics in LD

We expect that the transformation project will lead to an increase in the rate of genomic diagnoses in dementia and ID services. This in turn will facilitate personalised care and optimisation of a broad range of health outcomes.
We are doing this through;

- **Mapping mental health and genomic medicine working in the North Thames region.**
- **Undertaking a consultation on improving access to and ensuring equity in genomic investigation**
- **Development of model genomic testing pathways and virtual MDTs**
- **Creation of educational modules/resources for genomic testing in intellectual disability and dementia.**

We have largely completed the mapping exercise. Request data obtained from GOSH laboratory hub showed very low levels of requesting from mental health services.
A survey of consultant psychiatrists (ID services) has been completed and will inform pathway development and generation of educational resources. The testing pathways are currently being drafted within the framework of the Clinical Pathway Initiative.
Raising awareness of the project and dissemination of findings/outcomes has begun ,the project was presented at NHS Genomics Healthcare Summit in October 2022 and advertised at RCPsych ID Faculty annual meeting in November 2022.

Contributors-
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Notice

Faculty of intellectual disabilities prizes and bursaries

We are happy to announce the winners of the underlisted faculty prizes-

Alec Shapiro prize for specialty trainees ST1-6 winners
Dr Rubayat Jesmin (oral), and Jassdeep Rai (poster)

Jack Piachaud medical student poster prize winner-
Saima Ahmed

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 2024

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.

Brian Oliver Research Prize.

Deadline: 30 April 2024 for summary and 30 June 2024 for long entry
Prize: £500

Further details on applying for these prizes available on the webpage here