

# Psychiatry of Intellectual Disability

Newsletter of the Faculty of Psychiatry of Intellectual Disability

OCTOBER 2018 Vol 20, Issue 2



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# 70

**YEARS  
OF THE NHS  
1948 - 2018**

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Submitting articles: This is the Faculty members' newsletter and we encourage anyone to submit articles. The shorter the article and the more straightforward its language and style, the more likely it is to be read. We welcome thought-provoking and controversial material which might get a constructive response from readers.

Please email articles to either the [Editors](#) (psychidnewsletter@gmail.com) or [Kitti Kottasz](#), Faculty Committee Manager (intellectualdisability@rcpsych.ac.uk).

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## Editorial Group

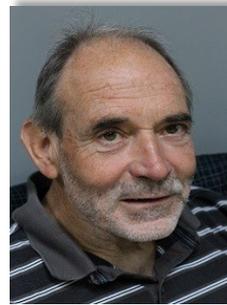


**Ken Courtenay**



**Giri Madhavan**

**Editor**



**Tom Berney**



**Elizabeth O'Rourke**

### **NHS 70/ Choose Psychiatry**

Welcome to the October 2018 edition of the Faculty Newsletter.

Much has happened since the April edition. Top of this has been the recent Exec elections. This has meant both saying thanks and warm goodbyes to outgoing Chair, Ashok Roy, and several members of the Exec (too numerous to list). This also means welcoming some new faces to the committee who you will be hearing from over the course of their terms. We wish them all well. A list of the Exec committee can be found [here](#).

It is fitting that this issue celebrates 70 years of the NHS with contributions from medical students, doctors at differing levels of training or non-training roles, and collaborative innovations with our GP colleagues and articles involving patient representatives. As part of this we're also highlighting the [Choose Psychiatry](#) campaign which reflects the need to attract the next generation of ID psychiatrists. We hope you enjoy this issue.

If you're subscribed to other Faculty newsletters you may already be aware of changes to how the newsletters are being produced on the college website by the College Digital Team. The new format aims to be consistent across the college faculties. Our format, which we produce ourselves, is therefore likely to change for future editions. Do let us know your thoughts about our current format via this [survey](#). If you have any strong views moving forward alternatively [email](#) or [tweet me](#). We'll aim to share these with the digital team.

Another noticeable change is that this and future editions will be only pdf (previously both pdf and web editions) and therefore there are no comments boxes. As you may recall from Tom's article in April last year, these were rarely completed. So moving forward we have been aiming to further integrate more common social media avenues to create interaction between members and Exec. This issue aims to push this forward. We will await responses.

If you're not subscribed to social media, then do [email](#) us and we'll also publish a few comments from social media in future editions to try to include as many as possible. If you are, on Twitter please use [#psychidnews](#) when referring to the newsletter.

As always, we welcome articles of interest to Faculty members. We look forward to seeing many of you at the [Annual Conference in October #PsychID2018](#).

[Giri Madhavan](#), October 2018





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**Dr Ken Courtenay**

**Chair of ID Faculty**

[@KenCourtenay](#)

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**Consultant in ID Psychiatry, Barnet Enfield and Haringey Mental Health NHS Trust**

This is my first 'View from the Chair' since being elected as Chair of the Faculty in June 2018. My thanks to the editor, Giri Madhavan, for all his work in steering the Newsletter so expertly to publication.

I am pleased to welcome seven new elected members to the Faculty Executive Committee contributing to the continued work of the Faculty. My thanks to those who have stepped down at the end of their terms of office.

I welcome Asit Biswas as our new Vice-Chair following my vacating the role. Asit is very experienced in working with the Faculty in his previous roles.

Mary Barrett has taken on the role of Chair of the Specialist Advisory Committee on Education and Training from John Russell who is Associate Dean for Curriculum.

The current key issues for the Faculty include the NHSE Transforming Care Programme and mental health legislation. It is wonderful news that Learning Disability is one of the four clinical priorities of the NHS 10 Year Plan from 2019 to 2029. Jean O'Hara, National Clinical Director, is leading on the Learning Disability component of the overall plan with consultations in September with clinicians, families, and patients. It has the potential to transform how people with Learning Disability are treated in the NHS and how services meet their needs. I know that members of the Executive Committee have been active in the NHSE engagement events.

The Mental Health Act Review in England and Wales is well underway. I have been involved in discussions in the College on Intellectual Disability and mental health legislation and have learned how important it is for the Faculty to be heard since our strength is in advocating for people with ID. The House of Lords has been considering changes to the Deprivation of Liberty Safeguards under the Mental Capacity Act. As a Community Psychiatrist, it is not difficult to see the limits

and challenges of the proposals and to bring practical perspectives to proposals that would have direct impacts on the people and families we work with.

I am looking forward to our Annual Residential Meeting in Liverpool on 4 – 5 October that is the highlight of our Faculty calendar. My thanks to Rohit Shankar for organising a great programme and pushing up the high standard of presentations we have become accustomed to. We are fortunate to have Adrian James, Registrar of the College, to speak to us on Thursday night. I am pleased that Roger Banks will deliver the Joze Jancar Lecture on Friday.

In the coming year I know there are many challenges ahead at a national level and importantly at a local level in our services. We will discuss some of them in Liverpool but it is important for you to maintain contact with the Executive Committee through your representatives and me to keep us aware of what is happening in your services.

I look forward to seeing many of you in Liverpool and for those of you keeping services going be sure to stay in touch.

**Ken Courtenay** ([ChairFacultyPID@rcpsych.ac.uk](mailto:ChairFacultyPID@rcpsych.ac.uk))

Chair, Faculty of Psychiatry of Intellectual Disability

Royal College of Psychiatrists UK

September 2018



# Research Roundup

**Rachel Steele**

*Clinical Librarian with Tees, Esk and Wear Valleys NHS Foundation Trust.*

[@TEWV library](#)



*Rachel Steele, Clinical Librarian with Tees Esk and Wear Valleys NHS Foundation Trust, begins the I-Spy Research Series with a discussion of sleep research in people with intellectual disabilities together with a round-up of the latest Intellectual Disability research available*

A recent systematic review (encompassing both single case and group studies) has been undertaken of the effects of behavioural approaches to sleep difficulties in people with a learning disability (Priday et al., 2017). The review highlighted how findings from group studies indicated significant improvements in sleep difficulties following behavioural interventions and that single case studies indicated that behavioural interventions are effective in improving sleep initiation and sleep maintenance problems but that the benefits longer-term may not be sustained (Priday et al., 2017). The overall conclusions are, therefore, that behavioural interventions may be a promising intervention for ameliorating sleep problems in people with intellectual disabilities but that further research is needed to confirm findings (Priday et al., 2017).

## Sleep and people with intellectual disabilities

There is a burgeoning interest in sleep in neuroscience and also in the popular press (Walker, 2017). A recent popular population highlights the vital role which sleep plays in improving, and maintaining, health and discusses features of the sleep process, such as the way in which REM sleep affects the human body and why sleep patterns change as we age (Walker, 2017).

This burgeoning interest in sleep appears to, not yet, have been translated specifically into research into the effects of sleep in people with intellectual disabilities.

However, in terms of the preliminary available research, a systematic review aimed to examine how sleep problems are classified in research among adults and older adults with intellectual disabilities and to collect information on the prevalence, associated factors and treatment of sleep problems in these groups (van de Wouw et al., 2012). The studies in the review varied in their methodological quality but, based on the available findings, the authors estimate that the overall prevalence rates of sleep problems in adults with learning disabilities ranged from 8.5% to 34.1%, with a prevalence of 9.2% being identified for significant sleep disorders (van de Wouw et al., 2012).

Sleep disorders were associated with challenging behaviour, respiratory disorders, visual impairment, mental health disorders and using psychotropic, antiepileptic and/or antidepressant drugs (de Wouw et al., 2012). However, while it is widely accepted that people in the general population sleep less as they age, the review found limited research has been conducted on people with learning disabilities and that, in general, research into sleep with people with intellectual disabilities has mainly relied on subjectively reported data rather than objective measure of sleep (de Wouw et al., 2012).

## I-Spy Round-Up

The Jo Cox Loneliness Commission aims to start a national conversation about loneliness in the UK. The first systematic review about the prevalence of, and interventions for, loneliness in people with intellectual disabilities has recently been released (Petroutsou et al., 2018). The five prevalence studies included in the review suggested an average loneliness prevalence of 44.74% in people with intellectual disabilities but most of the studies in the review were methodologically weak.

People with ID in the UK die approximately 16 years earlier than the general population (Heslop et al., 2014). It is important that mortality studies are conducted to explore the reasons why people with intellectual disabilities may experience these health inequalities. A systematic review of mortality studies raised concerns about the accuracy of Medical Certificates of Cause of Death (MCCD) in identifying cause of death; finding that intellectual disabilities were frequently underreported on MCCD (Shirton & Heslop, 2018).

Taking the theme of mortality further, a recent review found that people with Down syndrome died about 28 years earlier than the general population with congenital heart anomalies, comorbidities, low birthweight, Black and minority ethnicity, younger maternal age and poorer parental education contributing to earlier death (O'Leary et al., 2018).

Constipation may also contribute to serious health issues and death. A review article found that laxative use is the main management response to constipation in people with intellectual disability. The authors call for more research to confirm the pilot finding that an individualised, integrated bowel management programme may alleviate constipation in this group (Robertson et al., 2018).

## References

- Current policy dictates that people with intellectual disabilities should access mainstream services as far as possible, including mental health services such as IAPT. Dagnan et al. (2018) reported success in terms of therapist confidence, attitudes and therapeutic self-efficacy after a training course for IAPT therapists working with people with intellectual disabilities (Dagnan et al., 2018).
- Considering the perspectives of family members/support people of people with learning disabilities about what makes generalist mental health professionals effective, a qualitative study identified certain themes as being important: working together and differentiating between behaviour and mental health. They also wanted professionals to be able to discern meaning by interpreting multiple information sources and to acknowledge professional limitations (Weise et al., 2018).
- If people with intellectual disabilities should access mainstream (or specialist) services then they, or their relatives, sometimes may need to make complaints about the services they receive. A qualitative study explored families' experiences of making complaints in services. Three themes were identified: the nature and importance of concerns, relationships between families and staff and the process of raising concerns. A key finding was the centrality of "the little things" (Bright et al., 2018).
- Shame may also be a factor which contributes to the efficacy of psychological therapies for people with intellectual disabilities. A recent study found that people with mild to moderate learning disabilities may have difficulties with external, and internal, shame and this may increase psychological distress (Clapton et al., 2018).
- Accessing oral health care may be more challenging for people with learning disabilities than the general population. A recent qualitative study found that "personal and lifestyle influences" were often impediments to oral care (encompassing physical, sensory, cognitive, behavioural and affective factors) and "social and environmental factors" were often facilitators (such as caregiver support or oral hygiene routine (Chadwick et al., 2018).
- A recent study compared general and social anxiety and parental overprotection in a sample of 21 young adults with intellectual disabilities and in 21 young adults without intellectual disabilities. General, and social, anxiety were significantly greater in the group with intellectual disabilities and, while there were no differences in parental overprotection between the groups, qualitative data indicated that there were differences in experiences of social anxiety and parental overprotection between the two groups (Hemm et al., 2018).
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## Research Request

### **Severe behaviour problems and mental ill health in people with Prader-Willi Syndrome (PWS): understanding causation and developing new treatments.**

For many years, at the University of Cambridge, we have undertaken research the aims of which have been to characterize the nature of the severe behavioural and mental health problems commonly associated with having PWS and to develop better interventions.

These problems include the hyperphagia that develops in early childhood and the resultant risk of life-threatening obesity if access to food is not controlled; the severe temper outbursts, repetitive and ritualistic behaviours, severe skin picking, and mood disorders; and, particularly in those with the rarer disomy (UPD) form of PWS, a high risk of developing a severe psychotic illness in the teens or early adult life. We are now developing two new studies.

The first is focusing on further evaluating the use of a novel intervention (vagal nerve stimulation) for the treatment of the temper outbursts. This research arose following striking and serendipitous observations of marked improvements in behaviour observed in a trial aimed at improving the hyperphagia by using VNS (Manning et al 2016). A recent small trial, the findings of which are in submission, has used externally worn vagal nerve stimulators and has found similar results.

The second study is investigating the mechanisms that may explain the high risk for psychotic illness, particularly in those with the disomy (UPD) form of PWS. We are using clinical assessments, EEG and neuroimaging to test the hypotheses that an imbalance in GABA/glutamate levels in the brain and impaired sensory processing may explain this risk (see Aman et al 2018). Funding for the new VNS is being sought at present but we will be looking to recruit children and adults with PWS aged 8 years and older with a history of such behaviours. The psychosis study is now being undertaken and we have ethical approval for a pilot study to assess the methods we propose to use.

For the pilot study we are seeking to recruit adults with PWS, but for the main study we will be recruiting children and adults aged 12 years and older. If you know of anyone who you feel may be willing to be contacted by the research group could you e-mail Agnes Hoctor ([ah937@medschl.cam.ac.uk](mailto:ah937@medschl.cam.ac.uk)) saying that you would be willing to contact that person on our behalf in the future. We would then contact you again when that particular study has started and we have ethical approval. Thank you for your help. If you would like any further information do e-mail me directly ([ajh1008@medschl.cam.ac.uk](mailto:ajh1008@medschl.cam.ac.uk)).

Tony Holland

August, 2018

Aman et al (2018). Mechanistic insights into the genetics of affective psychosis in Prader-Willi syndrome. (2018) *The Lancet Psychiatry* 5(4) 370-378 doi: 10.1016/S2215-0366(18)30009-9

Manning et al (2016), Novel insights into maladaptive behaviours in Prader-Willi syndrome: serendipitous findings from an open trial of vagus nerve stimulation. *Journal of Intellectual Disability Research*, 60(2), 149-155.

*Requests for research are encouraged however publication in the Newsletter does not act as endorsement from the Faculty or College.*

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## RCPsych ID Psychiatry Spring Conference

**Dr Caroline Meade**

**Specialty Doctor**

**West Midlands**

*Joint spring meeting of the RCPsych Faculty of Intellectual Disability Psychiatry and British Psychological Society Division of Clinical Psychology Faculty for People with Intellectual Disabilities: 20th April 2018*

It was a gloriously hot and sunny April day; the perfect start to the Spring 2018 meeting. Delegates arrived early for refreshments and exhibition viewing, the sunshine seeming to boost already high levels of enthusiasm and interest.

The day started with a warm introduction from Dr. Ashok Roy, attending his last Faculty Conference in his role as Chair. Following this was an interesting morning of Keynote sessions. Prof Peter Langdon addressed the progress and challenges associated with undertaking psychological therapies in people with an intellectual disability. What I found particularly thought provoking was the fact that although adaptations are regularly made to tailor therapy for this population group, limited research means that we know little about its effectiveness. The presentation prompted discussion about whether specialist intellectual disability services should be supporting IAPT services to work with people with an intellectual disability. In the second Keynote session, Prof Andrew Jahoda presented his research trial looking at the use of Behaviour Activation Treatment for Depression (BEAT-IT) compared with a guided self-help attention control. People who are depressed tend to avoid activity leading to further reduction in mood and withdrawal, which the Behaviour Activation Treatment aims to tackle. Although the results showed no difference between the two interventions, there was a reduction in the depression score in both arms of the trial which was maintained at 12 months. I was intrigued to find that this presentation brought a particular service user to my mind; he has depression and his main difficulty seems to be an avoidance of activity. I wondered if BEAT-IT could be useful for him. Prof Jahoda highlighted that it is possible to carry out randomised control trials in people with an intellectual disability and continued perseverance in this area will help to tackle the issue that there is currently no evidence based treatments for this population group. The last Keynote session of

the morning was a stimulating presentation by Dr. Regi Alexander. Following on from the background of Winterbourne and Transforming Care, he outlined the findings from a recent NIHR funded study. This study compared the characteristic needs and care pathways of long-stay patients with and without intellectual disability within forensic psychiatric hospital settings in England. Despite similar forensic histories between the two groups, people with an intellectual disability were significantly less likely to go to prison. Dr. Alexander examined the implications of these findings and how we might be able to move forward to achieve better treatment outcomes for this group. A lively discussion ensued on a topic that people often feel very passionate about.

Following refreshments, a variety of workshops were on offer. Their diverse and appealing topics made choosing which one to attend quite a challenge! In the end I chose to attend 'STOMP: psychiatrists leading the way' facilitated by Dr. Ken Courtenay. Having recently completed my higher training in Psychiatry of Intellectual Disability and taken up my current role in a different Trust, I thought this subject would be highly relevant to my everyday practice. I certainly wasn't disappointed. The session allowed a fascinating group discussion about how colleagues are putting STOMP into practice in their own workplaces. We also identified barriers and thought about how these could potentially be addressed. I came away with a vast array of different ideas on this highly important subject and have already planned how to disseminate these to my current MDT. I heard positive feedback from the other three workshops, which were 'Working patterns in Intellectual Disability – challenging the myth – Psychiatry and Psychology' facilitated by Dr. Mohamed El-Tahir, 'Developing skills as an educator' facilitated by Dr. John Russell and a workshop chaired by Dr. Mark Lovell looking at the Ealing intensive therapeutic and short break service, which aims to prevent residential care for children and young people with an intellectual disability and challenging behaviour.

The lunch hour provided the opportunity for catching up with colleagues, reflection and continuation of the stimulating discussions stemming from the morning's activities. There was also a poster presentation display with posters covering an assortment of themes ranging from interventions for sleep difficulties to barriers to blood tests.

The afternoon kickstarted with another opportunity to choose a workshop to attend. On offer was 'Adapting mindfulness in an inpatient unit for people with Intellectual Disability' facilitated by Dr. Ceri Woodrow, 'An Introduction to Human Rights based risk assessment' facilitated by Dr. Beth Roberts, and a session led by Raphael Kelvin on The MindEd LDMH project which looks at education and training to sup-

port community support staff.



Having previously worked in a low secure forensic inpatient service, and currently working in a community learning disability service, I chose to attend the workshop on forensic risk assessments and management in community learning disability teams. This was facilitated by Dr. Adrian Burke. He outlined the service that he was involved in setting up in Cheshire and Wirral Partnership NHS Foundation Trust. The key take-home messages for me were being aware of the variety of risk assessment currently used and the problems this may cause when communicating risk between services, the importance of reviewing risk assessments and the need for a community forensic team to be integrated into the existing community service.

The Keynote sessions for the afternoon were chaired by Prof Nigel Beail. Geoff Bird gave a fascinating presentation asking the question 'Can Alexithymia explain (some of) the symptoms of Autism Spectrum Disorder?' It was a question that I had never contemplated before and I found myself enthralled by the research that Geoff presented. It seemed that many of the other delegates were similarly intrigued as an invigorating

and thought provoking discussion ensued including thinking about the increased prevalence of alexithymia in nearly all mental health conditions, state versus trait alexithymia and the fact that we don't actually know enough about the clinical implications of alexithymia. Dr. Magali-Fleur Barnoux followed with a presentation on the MATCH study which looked at people with autism who are detained in hospitals and the investigation of the face validity of eight proposed subtypes within this group. The day came towards its end with Dr. Allan Skelly's presentation on the importance of attachment informed working when working with people with an intellectual disability. The SECURED model was a very helpful acronym which I hope to be able to consider in my clinical practice, and I will certainly be discussing this topic with the psychologists within my team.

Dr. Roy reflected on the day, and as the conference came to a close there was a big thank you to him from the Faculty for all his hard work and dedication in his position as the Chair. He will be greatly missed in this role.

The delegates slowly left to enjoy the unseasonably warm evening, I'm sure with many learning points, reflections and perhaps questions to bring to their teams. The conference was thoroughly enjoyed by all. The next conference will be the Annual Conference in October 2018 and judging by the positive feedback from this conference, I have no doubt that it will be a great success.



*Several members of the Executive Committee prior to the ID Psychiatry Spring 2018 Conference*



### Child and Adolescent Intellectual Disability Psychiatry Network (CAIDPN) conference 10-11 May 2018

**Dr Elizabeth O'Rourke**

[@Eliz\\_ORourke](#)



*Higher Trainee*

*Psychiatry of Intellectual Disabilities*

*West Midlands Deanery*

[@CAIDPN1](#)

I was very fortunate to be successful in obtaining one of the three trainee bursaries to attend the CAIDPN conference this year. This year's conference was held at Windmill Village Hotel set in a picturesque part of the West Midlands countryside. Whilst the golfers were getting set for their game on a sunny morning, we settled down to listen to Dr Ashley Liew who gave a warm welcome to over 70 delegates from across the United Kingdom.

The day then began with a fascinating talk from Professor Chris Oliver on challenging behaviour. He highlighted the role that pain can play in self-injurious behaviour, especially in conditions of Cornelia de Lange and Tuberous Sclerosis. The assessment of pain using the [FLACC \(Face, Legs, Activity, Cry, Consolability\) pain scale](#) was recommended. Another top tip shared was to ask parents to record three clips where their child displays 'normal' behaviour, so if they present medically unwell doctors are able to see more clearly the difference in their presentation. A key learning point was that impulsivity (a child who cannot wait for things) is a key variable in increasing aggression and has a strong correlation in several syndromes.

Professor Vaso Totsika delivered a highly informative presentation on the early development of behavioural and emotional difficulties in children with Intellectual Disabilities (ID). It was emphasised that early adversity including poverty and poor maternal mental health is a risk factor for child behavioural problems. The take home message for me was that there is a large evidence base to support the fact that intervention in the form of parent training helps to protect against the later development of child behaviour problems. Delegates were signposted to [a new guide](#) for parents to help improve the well-being of young children with learning disabilities which has been published by Professor Richard Hastings of the University of Warwick.

Following lunch on the terrace there followed three workshops which covered a range of topics. I chose to attend a workshop on Systemic Approaches and Family Therapy which was facilitated by Dr Hiliary Howell. This was a really interactive session using group work to illustrate this form of therapy. The workshop highlighted the importance of

checking with families to see if they feel that an intervention has been helpful. I heard lots of very positive feedback from the other two workshops which were on Sensory Processing and Mental Health Approaches in Special Schools.

Phil Brayshaw presented an overview of how transforming care relates to children. There was a summary of NHS England's response to the Lenehan Review: ['Developing support and services for children and young people with a LD, Autism or both'](#) which is based on nine principles of a service model. This was followed by a lively debate: 'Transforming care is benefitting the psychiatric care of children with ID.' The session was very interactive as the audience used an electronic poll to determine their views before and after the debate. The proposer, Dr Roy, reminded the audience that it was the 7 year anniversary of the Winterbourne View abuse scandal. Dr Roy stressed that Transforming Care allowed professionals to talk openly and share good practice to create a vehicle by which services could be transformed. The opposer Dr Pru Allington-Smith gave an inspiring presentation and reminded the audience of the importance of early intervention, emphasising that self-injurious behaviour nearly always starts in the first 3 years of life. Dr Pru Allington-Smith urged the audience to read Dame Christine Lenehan's reviews into the care for children and young people with complex needs, ['These our are children'](#) and ['Good intentions, good enough'](#). It was stressed that change needs to take place in all areas which have been neglected for decades not just pockets of good practice. Dr Roy was thanked for supporting CAMHS-LD during his role as chair of the Faculty.

I attended the conference dinner which was superb. It provided a great chance to hear first-hand how CAMHS-ID services are being run in the different areas of the UK. I met a consultant I had emailed previously when completing a pre-hospital admission in Dundee.

Day two started promptly with the CAIDPN business meeting. There was positive discussion on how to engage more trainees in CAMHS-LD. Suggestions included a trainee representative position and trainee poster presentation prizes for future conferences.

Karen Bretherton was thanked for her contribution as chair of the CAIDPN for the previous three years.

There followed an informative discussion on alternatives to inpatient beds for CAMHS-LD which was led by Sue North and Jean O'Hara. The overarching theme was the importance of strong community teams with positive behavioural support, access to short break services and alignment with health, education and social care support.

Dr Caroline Richards gave an excellent presentation summa-

rising her extensive research into challenging behaviour and sleep Issues in children with autism and ID. Key learning points were the persistence of self-injurious behaviour in autism and that the profile of sleep disorder in autism appears different with sleep onset latency (resisting bedtime) and severe early morning waking. A top tip was shared to recommend the use of actigraphy to record sleep efficacy, and pre and post any sleep interventions.



After lunch there were physical health updates on autoimmune encephalopathies and feeding Issues. I

learnt that in autoimmune encephalopathies functional MRI is more likely to show an impairment than standard MRI and recovery can take up to 90 days. The conference concluded with a series of workshops which highlighted examples of

good practice and practical ways of working within transforming care. These included Birmingham Adult LD Intensive Support Team, Birmingham Pilot Enhancement of the 0-25 Urgent Care Service and the Leicester CAMHD-LD Outreach Service.

In summary, I found this was a very well organised conference which had a series of discussions and case examples interwoven with each presentation. I appreciated the opportunity to network with delegates who were really welcoming. I returned home with lots to read, think about and reflect on in the following weeks. I was extremely grateful to receive the bursary from the CAIDPN which allowed me to attend this event and would highly recommend that trainees apply for this in the future. The next CAIDPN conference will be held in Glasgow in May 2019 and I am looking forward to attending!

**To Join the CAIDPN network please email the chair Mark Lovell at [mark.lovell@nhs.net](mailto:mark.lovell@nhs.net)**





## Neurodevelopmental Psychiatry Day Event

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**Dr Nasreen Shaikh**

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*ST5 in Psychiatry of Intellectual Disability*

The first East Midlands Neurodevelopmental Psychiatry Study Day for medical students and junior doctors took place at the George Davies Centre, University of Leicester on Friday 15<sup>th</sup> June 2018. The programme was busy and varied, covering all aspects of training. Speakers were regional practicing clinicians and leaders in their field.

### Aims

Organisation of the event was a joint effort between consultants and Specialist trainees in ID from Nottinghamshire Healthcare Trust and Leicestershire Partnership Trust. These were myself, Dr Chaya Kapugama (ST5), Dr Samuel Tromans (ST5), Dr Mary Barrett, Dr Shweta Gangavati and Dr Niraj Singh who was the main lead for the project.

We noted the current issues with recruiting doctors into ID and reflected on how this could be overcome. Typically junior doctors are exposed to ID once they are a core trainee in psychiatry when they MAY do an attachment (though a lot of people such as myself did not get this opportunity).

Particularly we wondered whether interest in the specialty could be sparked at an earlier stage e.g. as a medical student. Is it ever too early to stimulate an interest in psychiatry and particularly Intellectual disability? In Nottingham some medical students get the chance to do an attachment in ID. They also get lecture-based teaching as part of the curriculum.

Having said this we did not set about for it to be purely a "careers event" and hoped from another angle that it would make students/junior doctors aware of this population and the difficulties they encounter as well as the role of the ID Psychiatrist.

Thus the event was aimed at medical students and junior doctors to stimulate interest in ID as a specialty (both from the perspective of a future career option but also in those who may pursue other specialties).

We opened the event initially to regional medical students and junior doctors (comprising foundation year doctors and core trainees in psychiatry). However we also opened it to people from outside these regions and contacted the various PsychSoc groups based within medical schools.

### Design of the programme

Our approach was to have a varied programme which allowed provided delegates a mixture of "core" topics of interest such as autism, ADHD, forensics and Epilepsy. We also wanted delegates to learn about development opportunities within ID as a specialty hence we felt that there should be talks on leadership and research. An understanding of the MDT approach which is different for ID compared to other specialties within Psychiatry was also felt necessary. In addition we felt it would be useful for them to talk to someone who was junior and had worked in Intellectual Disability such as a foundation year doctor. Taking into account time constraints, the focus of the programme was on breadth rather than depth.

### The flyer

The flyer for the event was designed primarily by myself and Dr Kapugama with input from the rest of the team. The main image was taken from the book "Sonia's feeling sad" by Professor Shelia Hollins and Roger Banks (illustrated by Lisa Kopper). It is one of the books from the "Beyond Words" series and focuses on a young woman with an ID who develops depression. We obtained permission from "Beyond Words" to use the image which shows a doctor communicating with a young woman with an intellectual disability by asking her to point to a symbol to demonstrate how she feels. I liked this image as it focused on the relationship between the doctor and patient and the need to pay special attention to the method of communication in those with an ID. The book is ambiguous about the specialty of the doctor but illustrates how they can make a difference to someone with an intellectual disability.

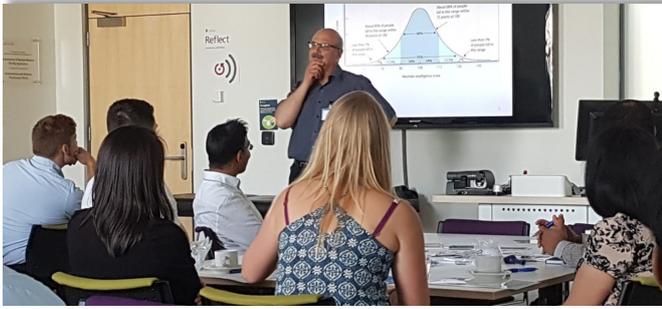
### The Event

The event was attended by 31 delegates, including 20 medical students, 5 core trainees, 2 GP trainees and 2 from other professions. Delegates were mainly from the East Midlands Region; however a few came from further afield.

Our Chair was Dr Niraj Singh who is a community consultant (Nottinghamshire Healthcare Trust) and also works with the ICATT service (Intensive Community Assessment and Treatment team).

An enthusiastic welcome address was provided by Dr Pete Miller, Chief Executive of Leicestershire Partnership Trust.

Dr Peter Cutajar (pictured below) presented the first key clinical topic of the day "Introduction to Intellectual Disability".



Next up was ST5 Dr Chaya Kapugama who did the “**interview with Professor Sabyasachi Bhaumik**” which was warmly received by delegates. Professor Bhaumik is well known for his contributions to ID Psychiatry (he was awarded an OBE for services to medicine in 2006). Professor Bhaumik answered a broad range of questions which included how he came into psychiatry and ID as well as his research/management experience. He also talked about what links ID has to other specialties of psychiatry and to medicine overall.

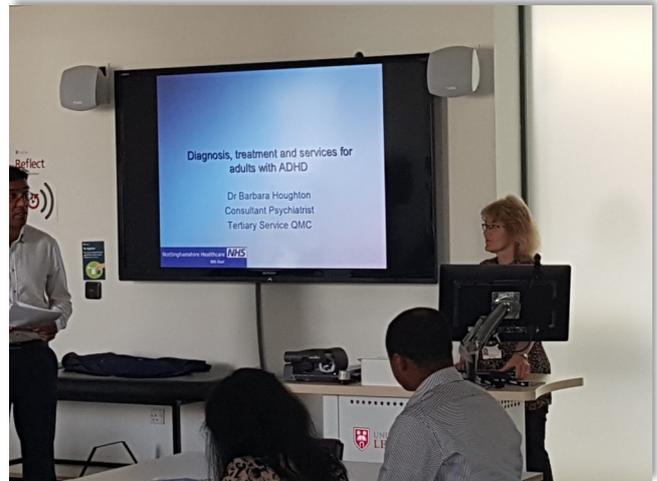


Dr Mary Barrett (pictured below) is based at the Agnes Unit in Leicester and has a special interest in Autism. She works with the Adult Autism Assessment Service in Leicester General Hospital. She gave delegates an **overview of Autism** as well as pointing them to further resources. At the end of her presentation she invited delegates to come and learn more by joining her in clinic for shadowing.



Dr Barbara Houghton (pictured below) is a community con-

sultant and also sole inpatient consultant for Alexander a locked rehabilitation unit for men with ID . She talked to delegates about **assessment and management aspects of ADHD**.



The **epilepsy presentation** was delivered by Dr Samuel Tromans (ST5) who is an Honorary Academic Clinical lecturer at University of Leicester where he is undertaking a PhD on the epidemiology of autism in inpatient settings.

We also had a presentation on **Forensic psychiatry within ID** services which was delivered by Dr Abdul Shaikh. Dr Shaikh works with offenders with ID in a Regional ID male low secure unit at the Wells Road centre and also in the community with the community forensic team.

Following this there was a lunch break which allowed delegates time to network both amongst themselves as well as with professionals. We were fortunate that some of the speakers were able to stay with us for the whole day. It also provided delegates an opportunity to look at the posters. A couple of the posters showed projects that medical students had been involved in (these were kindly provided by Professor Penny Standen).

The afternoon presentations included “**introducing the MDT**”, presented by Dr Heidi Higgins (clinical psychologist), Chris Burston (clinical nurse), Amanda Oliver (community nurse) and Jennifer Roberts (Speech and Language therapist). MDT working was thoughtfully illustrated using a real-life case study of a patient who was referred by her GP who queried both depression and a diagnosis of ID . Interestingly they also looked at the different stages in the case and how the needs of the MDT changed accordingly.

Dr Richard Lansdall-Welfare, clinical Director for specialist services in Nottinghamshire Healthcare trust , presented on **Leadership**. He spoke of his personal journey and how he had benefitted in terms of professional development from experiences such as the Kings Fund course as well as the Trent Travel award through which he got to see ID services in America and the contrast between regions. He also talked about his work with charities in Sarajevo, Bosnia and change in services in the UK and Transforming care.

Dr Ben Ross, a ST6 Registrar in Nottingham, did an informally styled **case study session**. He introduced the audience to the case of a male patient with ID who presents to their GP with challenging behaviour. Delegates had to work in groups and think about what may be the contributing causes which were discussed afterwards. The session allowed delegates to get a taste of the types of problems we deal with and to join in the problem solving process.

Dr Regi Alexander, consultant psychiatrist with Hertfordshire Partnership University NHS Foundation trust and an Honorary senior lecturer at University of Leicester did the next talk with Dr Tromans. They spoke to delegates about research and **academic opportunities** within ID.

Dr Benjamin Gerrins (FY2, Nottingham) talked about **“The FY2 Experience”**. As a trainee who does not have plans to go into psychiatry he provided a different perspective and was able to reflect on what a junior doctor could hope to get from the job. In particular he talked about the chance to learn about patients in depth and making a difference.

The **finishing comments** were kindly provided by Dr Asit Biswas, Honorary Associate Professor at the University of Leicester, and provided some useful pointers as to what delegates could do next if they wanted to find out more about ID e.g. joining the Royal College of Psychiatry. He also talked about resources such as Fellowships and Bursaries that may be available. He encouraged students to try for prizes and mentioned the RCPsych Trent division “medical student public speaking competition” as well as the Professor Joan Bicknell medical student essay prize and the Jack Piachaud Medical Student Poster Prize.

### Feedback

Overall feedback from the delegates was really positive.

- 80% delegates agreed that their interest in psychiatry had increased following the event which was really positive.
- 87% delegates agreed their understanding of the needs of patients with neuropsychiatric conditions had increased following the event.
- 93% of delegates agreed that events like this helped encourage recruitment to psychiatry.

Positive comments included “fab speakers” “good range of speakers and all very passionate which was inspiring” “thank you for a lovely day” “really good talks from everyone” “certain stand out sessions have definitely made me think about psychiatry. Thank you for organising this as a first time as no other department has!”

Some delegates commented that certain topics would have benefitted from more time allocated. Some seemed to prefer “core topics” whereas others appeared to enjoy the more biographical talks where speakers talked about their journeys.

Following the event, delegates got in touch with us to request slides and contacts. We are providing a list of contacts and further information which includes links to useful resources such as the **“choose psychiatry”** section of the Royal College website.

We were really pleased with the response and feel it provides evidence for a) the need and b) the effectiveness of such events. We hope to repeat similar events in the future.





## UCL STOMP Alternatives Research Seminar: update

**Dr Rory Sheehan et al.**

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The STOMP (Stopping Overmedication of People with a Learning Disability, Autism or both) programme is a call to action to increase awareness and bring about change in the practice of prescribing psychotropic medication for people with intellectual disabilities (ID) and/or autism (referred to as intellectual developmental disabilities, IDD throughout) and challenging behaviour across the lifespan (NHS England, 2015). There is now overwhelming evidence from research that shows that people with IDD are more likely to receive psychotropic medication in the absence of a diagnosed mental disorder. In addition, family carers have expressed concerns over time about current practice and have identified several shortcomings regarding the prescription and monitoring of psychotropics. These range from not being listened to or consulted at the point of prescribing; lack of alternatives including psychosocial interventions, e.g. Positive Behavioural Support (PBS) and a variation in practice that sees some areas having greater proportion of adults with IDD admitted to assessment and treatment units than others.

As part of our engagement with the STOMP programme we proposed to hold a day seminar to look at research findings across the spectrum of mental disorders and to hear about examples of good practice within STOMP with the view of contributing to the perspectives for the next phase(s) of the programme.

A number of invited stakeholders attended the day including parent representative (Hazel Griffiths and Viv Cooper from the Challenging Behaviour Foundation), STOMP leadership (David Gerrard, Anne Webster and David Branford), UCL Psychiatry based academics (Angela Hassiotis, Rory

Sheehan, Andrew Sommerlad), clinical colleagues (Jen Rhodes, Sunderland; Charlotte Pretorius and Becky Goodey, Cornwall), and the chair and vice chair of the Faculty of the Psychiatry of Intellectual Disabilities (Ashok Roy and Ken Courtenay).

The seminar which was held on 26<sup>th</sup> of October 2017 included presentations that covered a number of approaches to the issue of overprescribing including clinical examples in Sunderland and Cornwall, a summary of the progress made by a similar campaign in dementia care and an oversight of medication reviews as interventions interspersed with questions and answers.

Hazel, a family carer, gave a powerful presentation of her son's recovery once he was taken off the psychotropic medications and received PBS. An extract is included below (Hazel contributed a longer version to a book on family carers' experience of Positive Behaviour Support (PBS), edited by Dr Tanja Sappok).

*"I found PBS worked in helping to support our son who has autism and catatonia. My son has had previous medical based and restrictive interventions involving, institutionalisation, a containment model of care using harsh, behaviour modification, intimidation, abusive language and illicit fear. PBS has had an equally positive effect on not only my son's wellbeing and life experiences but the family's too. We found a positive behaviour support plan was essential to understand what triggers my son's distress and how to reduce these triggers. The plan identified how as a family we could make changes to our behaviour, perceptions and reactions. How important it was to understand autism. We had to step into his world and try and imagine how our son sees and feels the world. "*

A striking feature of the practice examples outlined by professionals, was the collaborative, multidisciplinary nature of the new services especially bringing pharmacists and primary care practitioners together as participants in those approaches. The services we heard about are all new developments and we did not have any data to compare against, but they appeared to be making a difference in the patient engagement and have led to some successful cases of improved quality of life linked to reduction and even discontinuation of psychotropic medications. More specifically, the participants valued

- a multidisciplinary approach to managing challenging behaviour
- having a clear clinical processes about medication

- prescribing and monitoring;
- education of prescribers and carers;
- prompt application of positive behaviour support principles and functional assessment;
- access to skilled workforce;
- which appear to have contributed to early successes in managing reduction of psychotropic medication.

At the same time, challenges were also evident including persuading professionals and carers that this can be done and combating entrenched professional attitudes; equipping care staff with problem solving skills to manage emergencies; sharing information and knowledge between professionals and services, e.g. primary and secondary care.

Andrew Sommerlad, Wellcome Doctoral Fellow, presented current data on the management of agitation and other behavioural problems in older people suffering with dementia. As many as 50% of those with dementia were receiving antipsychotics in the 90s. However, those drugs were linked to greater risk of stroke with a number of warnings issued between 2002-2005. This practice has been tackled on a number of fronts such as training on dementia for all care home staff, introduction of protocols for the use of antipsychotics and national audits of practice.

A Call to Action proposed a 30% reduction in antipsychotics over 3 years. At the same time there was considerable drive to provide alternatives such as psychosocial interventions for behavioural problems and agitation and improve safe prescribing. All of those initiatives led to impact as rates of prescriptions of both typical and atypical antipsychotic medications have been decreasing as shown by primary care data (Donergan et al, the Lancet 2017). However, some caution is advised given that other recent research suggests that in severe cases small doses of antipsychotics can be helpful and trials of withdrawal lead to higher rates of relapse. This work in the field of dementia has many similarities to the proposed strategy in IDD. While it is not identical, there are many valuable lessons that can be learnt and used within the STOMP project.

Rory Sheehan, NIHR Doctoral Fellow, talked about the state of the art in psychotropic prescribing in people with ID. The main issues are polypharmacy and high rates of antipsychotic prescribing without licensed indication. Lack of understanding of challenging behaviour, the presence of autism spectrum disorder, lack of awareness of, and access to psychosocial alternatives or medication being perceived as helpful may underlie the prescribing rationale. Two approaches were suggested: 1) optimising the prescription of psychotropic medication or 2) de-prescribing which is the main thrust of the STOMP campaign. Regarding the latter, Anderson et al (2014) suggest that a number of factors may either act as enablers or barriers including awareness, prescriber and carer inertia,

self-efficacy (data availability, skill or knowledge to follow a course of action, access to specialist support) and finally feasibility (a systemic approach to prescribing including regulation and access to services, professionals and the individual and his/her network).



(L-R, back) Ken Courtenay, Andrew Sommerlad, Anne Webster, Jen Rhodes,  
(L-R, front) Dave Branford, Sophie Dodwell, Julian Morris

Both the approach from the dementia Call to Action and the research evidence in IDD shows that political will, research into alternatives to medication, and organisational and professional contexts are essential in ensuring long term impact.

As the NHS England STOMP team will complete its work by March 2019, there is an urgency to ensure sustainability and an enduring influence on positives that have been achieved to date. An important objective for NHSE leads is to focus on building STOMP into systems that will ensure longevity of the programme aims beyond the end date. Joint working with stakeholders, e.g. Learning Disability Senate, Royal College of Psychiatrists Faculty of the Psychiatry of Intellectual Disability and primary care annual health checks is pivotal to medium and long term success.

The attendees came up with a number of ideas about steps that the STOMP initiative could take or would benefit from. There is a research recommendation about further investigation of antipsychotic medication alone or in combination with a psychosocial approach (NICE, 2015). It is questionable at this stage whether such a trial may be a viable direction but worth considering.

There is current evidence that PBS application or delivery does not affect sufficiently psychotropic medication prescribing, especially rates of withdrawal (Hassiotis et al, 2018). Several recent randomised controlled trials which have attempted to address the issue of psychotropic/antipsychotic medication reduction were unable to recruit the required number of participants both in the UK and elsewhere. Clearly, there are lessons to be learnt from

those projects, which may throw light on the wider issue of reluctance or inability to exert greater influence on the initiation and continuation of prescribing. This is particularly important given the high placebo effect of pharmacological interventions.



(L-R) Charlotte Pretorius, Becky Goodey, Viv Cooper, Dave Gerrard

Despite those arguments about the short and longer term impact of STOMP, it is a welcome initiative that has been raising awareness and has brought many stakeholders together to think about changing practice. Perhaps, the STOMP team should consider taking a more nuanced approach asking what is it that stops people from engaging in new approaches rather than maintaining practice. It is likely that the answers will take in individual, systemic/organisational and societal aspects that no campaign can hope to address fully within a limited timeframe.

We believe that such engagement events are really important in progressing the agenda and ensuring that policy makers, clinicians and researchers converge on their approaches to ensure the improvement of quality of life and reduction in inequalities.

Find out more about STOMP [here](https://www.vodg.org.uk/campaigns/stompcampaign/) (https://www.vodg.org.uk/campaigns/stompcampaign/) And [here](https://www.england.nhs.uk/learning-disabilities/improving-health/stomp/). (https://www.england.nhs.uk/learning-disabilities/improving-health/stomp/)

The site contains resources for professionals, carers and service users to help with medication reviews.

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# Joan Bicknell Prizewinner

**Manisha Natarajan**

*3rd Year medical student at Queen's  
University Belfast*

## Introduction

In my first year of medicine, I participated in a Student Selected Component (SSC) entitled 'Working with Children with Disabilities.' During this module, we were assigned a child from the school in which we were based to shadow for 12 weeks and produce a case study on. Alongside this, we spent time with the multidisciplinary team of therapists and doctors who cared for the kids and had lectures on specific common conditions seen in the school.

For my case study, I worked with a boy who had Global Developmental Delay (with suspected Autism) sadly not a condition the school had much experience with. I felt thrown in at the deep end with a 'difficult' child who couldn't communicate much apart from signalling 'yes' or 'no' to simple questions and seemed to enjoy actively ignoring me. Initially I found the experience extremely frustrating and difficult but I slowly made progress through engaging with his family and spending more time with him. I was delighted with how my efforts paid off when we gradually managed to develop a good rapport.

The sense of satisfaction and confidence gained at overcoming the communication and behavioural hurdles between us led me towards another SSC called 'Working with Adults with Learning Disabilities (LD)' in my second year. This course involved spending afternoons at a day centre for adults with LD, supported by lectures about some biopsychosocial aspects of LD such as communication issues, healthcare inequalities and stigma. As coursework, we created a healthcare leaflet aimed at those with LD and prepared a debate on the sensitive subject, 'this house believes there should be eradication of antenatally identifiable causes of learning disability'.

Before medical school, a brief volunteering scheme had served as my only exposure to anyone with severe disabilities. The course in my first year had set clear boundaries between us and the kids; the visible age difference gave us as adult's authority which allowed me to stay within my comfort zone. I therefore wanted to challenge myself and see how the dynamic and process of rapport-building would change when working with adults. Having spent 12 weeks getting to know the kids in my first year SSC and witnessing a positive example of the educational years of those with sig-

nificant disabilities, I was also curious to know what the possibilities were for their future. Moreover, I had gained a great deal of confidence through patient interactions during my second year and wanted to take advantage of that by doing a communicatively challenging course and hopefully further improving these skills.

My decision was confirmed when I realised we would only receive one day of formal training in care of those with Learning Disabilities as medical students, despite LD affecting 1-2% of the population (Emerson et al, 2010).

## First Impressions

Before the course started, I was nervous about what to expect. It had felt very safe and monitored within the school environment of my previous disability module in first year. However, I knew that working with adults would be extremely different. I had only ever seen adults with learning disabilities through the biased filter of film and media which seemed to present those with LD as either sweet-natured adults whose social blunders were the object of jokes, or nightmarish characters who would never be understood or accepted by society.

During my previous degree in Social Anthropology, I had become interested in how societal prejudice and discriminatory environments are created through constantly repeated misrepresentations about minority groups. Persistent reiteration of falsehoods about less sociocultural powerful groups makes them self-perpetuating and endemic within that society. Though I knew depictions of the LD community were not accurate, I was still left feeling anxious about the unknown.

## The Day Centre

Our first day at the centre allowed us to become acquainted with a few key staff members, learn about the history and functioning of the organisation and be introduced to some clients. I knew the adults were probably going to have quite severe difficulties and, having been inundated with media presenting institutions for severe LD care as 'mad houses', I was surprised to see how ordinary the centre was. After working with children with disabilities (learning and physical), I had naively believed that I had confronted and overcome my prejudices regarding disabilities so that I could do this course with a completely open mind.

Reflecting on my initial reactions to the centre, I realised that my fear and preconceptions about it were evidence of deep-seated beliefs about disabilities. My expectations had been that clients would barely be able to engage with me or would possibly even act out, making interaction difficult. In fact, on that first day, the kindness and chattiness of the clients was equal to that of the staff. Those who were non-verbal were

keen to introduce themselves to me in whatever way possible. I learnt two valuable lessons for my future in medicine: firstly, to be continuously self-critical of my beliefs and secondly, to treat every person as an individual by relinquishing assumptions.



My anthropology degree delved briefly into disability studies, focussing on disability rights. I had embraced the liberal, left-wing concept that much of disability is created and reinforced by 'disabling spaces' (Reid-Cunningham, 2009). Though my views on this matter have been tempered with a rational understanding of the biopsychosocial impact of medical pathologies underlying disability, I can still clearly observe that our public spaces could be made much more 'enabling' for those with disabilities.

The centre, which was built in partnership with the clients, was an example of how public spaces could be tweaked to be made more disabled friendly. Areas were big with even ground for mobility impairments with some rooms dedicated to those who had specific needs, such as one man who adored aeroplanes and running around during the day but was at risk of falling or wandering outside the compound if left unattended. The day centre provided him with a large soft room decked with aeroplane paraphernalia so that he could do what he loved all day. They had also built various multi-sensory rooms designed with Autism in mind but used for relaxation by a multitude of clients with diverse diagnoses. It was emphasised that those who attended the centre considered it their workplace, so it was even more important that they felt enabled to be at their best. Some adjustments were not so ideal, such as the health and safety rule that the toilet door was left unlocked if one of the clients went in alone. There was an 'occupied' sign outside but it didn't always work as intended and I heard of a few instances when people had accidentally walked in on others. However, the importance of an accommodating management style so that organisations fit the requirements of those who use them (rather than the other way around) was emphasised.

Maintaining a flexible attitude to make spaces more accessible and enabling for all is also relevant in terms of education-health and otherwise. While researching LD-suitable health leaflets for coursework, I realised how materials could be made more universally comprehensible by simply using clearer fonts and pictures. I was also lucky to attend a sex educa-

tion class for men in the day centre held by an external teacher which was timetabled just before a Valentine's Day dance. I had wanted to learn how a lesson about a tricky subject could be effectively taught to a big group with extremely diverse learning abilities so was glad for the opportunity to observe. The teacher began by gently dealing with less taboo issues of privacy, moving on to appropriate social behaviour and then gradually broached the subject of relationships and sex in relation to suitable behaviours. I appreciated the simple brilliance of engaging the men in more palatable discussion to bring ease to the group, and then using that conversation as a seamless segue into sex education. Overall, the students seemed to engage well with the class and the teacher encouraged everyone to contribute in their own way, which was not easy as most were keen to join in with the dance happening down the hall. Creating suitable spaces and accessible education sessions for clients is a priority for the centre; I saw that this helps clients gain a sense of independence.

### Independence and Confidence

Self-reliance understandably came up time and time again in some form or another during this course. Whether it was the centre's head social worker explaining the attached 'practice home' in which clients can trial living independently under the distant supervision of staff, or during the debate when discussion turned to the debilitating effect of parenting a life-long dependent, it is evident that gaining a degree of self-sufficiency within individual means is central to a good quality of life for both the LD community and their loved ones.

The clients at the day centre who I talked to seemed proud that they came for their working day there. The staff pushed them to fulfil their potential as best as possible; those who were good communicators were encouraged to help others, show visitors around and even take responsibility for the reception desk. Everyone had a daily agenda of activities to complete matched to their interests and abilities. On my last day, I met a woman who was giggling with glee because she had just found out that her excellent work in helping organise people on a recent day out had earned her a regular paid job as an assistant for fun excursions from centres in the area. People I spoke to had a sense of purpose, self-sufficiency and value that partly came from the respect and opportunities staff members afforded them.

Having grown up with a privileged background, I had not appreciated the confidence I had gained from being given respect and recognition for achievements. I was used to being provided with certificates (sometimes during ceremonies) for many of my accomplishments, though the pomp always seemed superfluous.

We were fortunate to go to the awards ceremony for a rehabilitation programme run by the Department of Justice (DOJ) for learning disabled people who have committed serious crimes. It was a wonderful scheme which compelled those involved to confront their wrongdoings and work through their psychological issues through the medium of short films. Film-making occurred alongside being provided with profes-

sional and peer-group support. The audience watched the films that participants had written, staged, filmed and edited all themselves and then they were given a graduation certificate for completion of a higher educational qualification in film-making. For most of these men, this was the only graduation ceremony they had ever been to and their delight and pride in this achievement was tangible to the crowd. The father of a participant who had made one particularly harrowing film touchingly addressed the audience at the end to express his gratitude for the programme which he said had 'given him his son back'. I was so moved by the whole occasion and felt foolish and self-centred to not have considered the importance of recognition and respect in relation to my own life and other's. To have your positive achievements celebrated increases the self-respect and confidence which urges people to continue trying to grow and achieve. Dialogue surrounding the learning-disabled community is rarely empowering in this way so it was inspiring to see this event and the awesome effect it had on the participants.

### Stigma

The day centre and the DOJ's programme for those with learning disabilities seemed to have a profound impact on those who were involved in it, including me. I started being much more critical about things I witnessed on a day-to-day basis about disabilities of any kind. I think this awareness and constant critique is important for all future practitioners of medicine. The treatment decisions we will make in future require a full understanding of the issues, which is not gleaned from the usual discourse about learning disability.

While preparing for the debate, I found that discussion about the worth to society of people who have LD is sorely lacking in the public forum. There was a recent government policy suggestion (Stratton, 2011) to reduce unemployment amongst the disabled. A parliamentary member stated that business owners could be encouraged into giving jobs to those with learning disabilities by creating a lower minimum wage for the learning disabled. While lowering the barrier of minimum wage would possibly improve the unemployment issues (Monckton, 2016) this proposal implies that those within the LD community are sufficiently 'other' that work done by them is worth less than by those without learning disabilities. These concepts reinforce stigma and are likely to ostracise and further erode the confidence of members of the LD community. Policies such as these hinder rather than help those with LD by not addressing the underlying causes of unemployment for the learning disabled, including societal prejudice and lack of targeted training or educational programmes.

### Healthcare

In relation to healthcare, a largely negative public dialogue surrounding learning disability feeds into already deeply held societal prejudices, so it is difficult to make impartial and fair decisions related to LD. The session about healthcare inequalities highlighted that prejudices form unnecessary obstacles for that community. The inequalities were proven to be large-

ly founded on systemic prejudice resulting in inadequate communication and care for LD patients (Wilson, 2017). Tragically, this has resulted in 37% (ibid) of deaths of people with learning disabilities being avoidable.

One of the notable things that I learnt from my experience in the day centre was that usually my difficulties with interactions were due to my own timidity and rigidity about communication methods. When I attempted different ways of putting my message across by universal sign language or by just saying things in a different style, I was normally understood. If that still did not work, there was always a support worker there who could show me a better way of communicating. Before this, I had assumed communication would be frustratingly hard with people with serious learning disabilities. However, when I compared my interactions in clinical attachments to those I had in the day centre, I saw that I used similar manipulations in language and communication to get complex points across. I believe it was vital that I learn and share this observation as I am sure that many healthcare workers make similar mistakes of assuming they will never be understood by learning disabled patients so do not even try.



### Conclusion

I feel lucky to have done this module, particularly since we will only receive minimal training in treating those with learning disabilities as junior doctors. I was quite surprised by my reactions to the day centre and the LD community, considering my experiences working with children in first year. I think I managed to distance myself from the situation while with the young kids whereas working with adults seemed to touch a nerve. The fact we were all adults made it impossible for me not to compare my life to theirs and I grasped just how different their opportunities and daily lives were. Having a debate on the sensitive topic of pre-natal eradication of LD helped to focus the lessons I had learned from this module. I have always been extremely pro-choice but had to consider arguments from a pro-life stance for the debate.

Tying together my experiences of the DOJ graduation ceremony, my interactions at the day centre and the lectures we had, the debate highlighted the hugely damaging effect of the negative attitudes towards LD which permeate through society. These attitudes reinforce the societal stigma which

thwarts the efforts of those with learning disabilities, slowly eroding confidence and quality of life.

Organisations such as the day centre do a fantastic job of encouraging those with learning disabilities to reach their potential. However much more must be done to improve LD status and I hope I can be an advocate for change in my future work as a doctor. I have gained an awareness of my own prejudiced beliefs as well as an understanding that there are many ways of directly interacting with a patient. All communication methods and facilities must be utilised if necessary, as omitting effective patient communication is not an option; it can have dreadful consequences in healthcare, ranging from misdiagnoses to avoidable deaths. It is a shame that my medical student peers will not share my experiences of LD: the important lessons I learned from this module will be invaluable to my practice as a doctor when treating all patients, not just those with learning disabilities.

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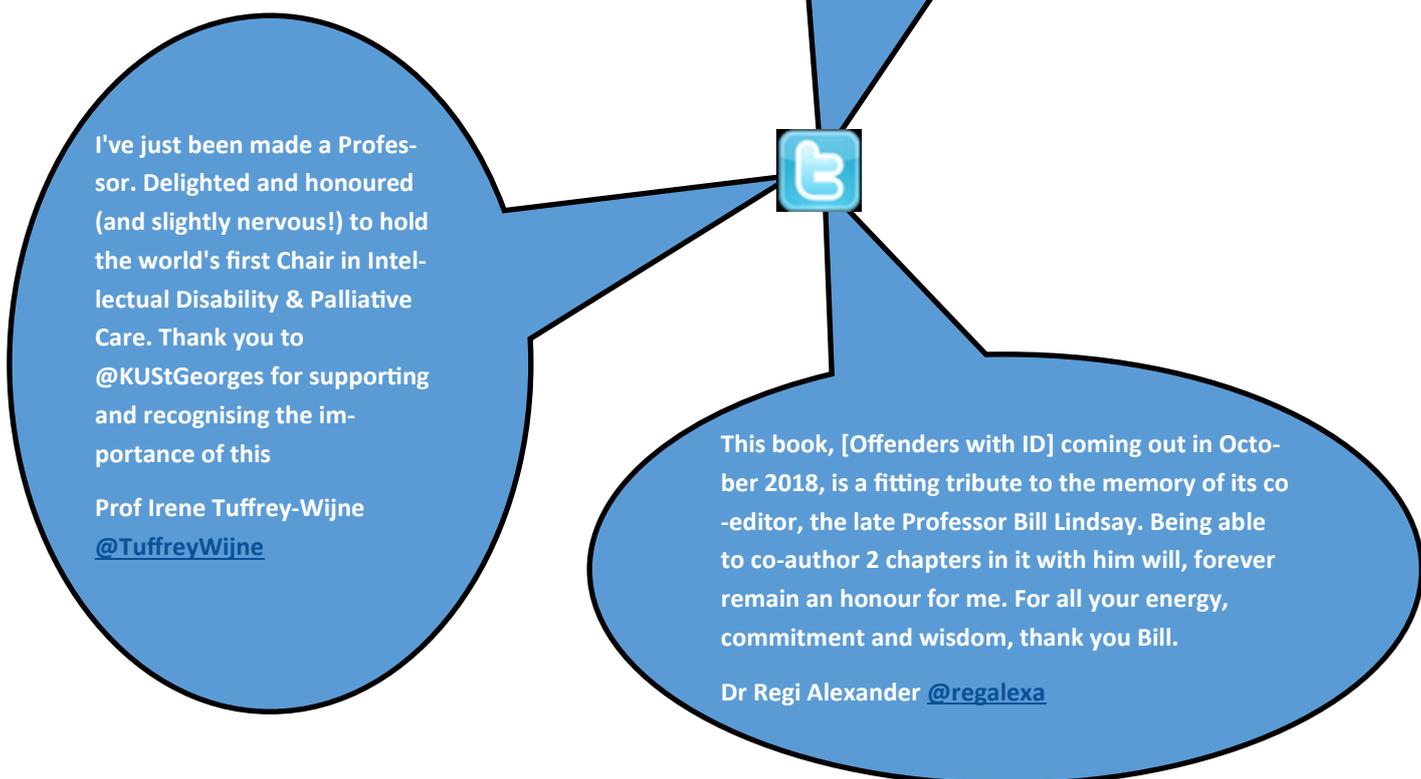
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Wilson, C., (2017) Health Inequalities, [lecture] Working with People with Learning Disabilities, MED2017, Queen's University Belfast, 21.02.2017

In case you missed it: Social Media



Dr. Perera highlighting how Annual Health Checks in People with ID reveal health inequalities. Health in ID is everyone's business.  
Dr Ken Courtenay [@KenCourtenay](#)

I've just been made a Professor. Delighted and honoured (and slightly nervous!) to hold the world's first Chair in Intellectual Disability & Palliative Care. Thank you to [@KUSTGeorges](#) for supporting and recognising the importance of this  
Prof Irene Tuffrey-Wijne [@TuffreyWijne](#)

This book, [Offenders with ID] coming out in October 2018, is a fitting tribute to the memory of its co-editor, the late Professor Bill Lindsay. Being able to co-author 2 chapters in it with him will, forever remain an honour for me. For all your energy, commitment and wisdom, thank you Bill.  
Dr Regi Alexander [@regalex](#)



## Gregory O'Brien Prizewinner (2016)

**Dr Lilly Lines**

*Consultant ID Psychiatrist*



I am grateful to the RCPsych ID Faculty, to South London and the Maudsley and to the recipient organisations and clinicians for the two and half weeks I spent in Ontario. My observership took me to the Center for Addiction and Mental Health (CAMH) in Toronto for two weeks, with additional time spent with inspiring clinicians at the University of Toronto and at MacHealth in Hamilton during another trip.

In Ontario many psychiatrists are attached to an academic institution. The University of Toronto has hundreds of associate professors, who are not on the University payroll. Psychiatrists practice across a range of options, from full time private practice, billing the provincial government on a fee for service basis, to salaried employment in a clinical institution, via everything in between, such as a mix of private practice and salaried, or sessional work to institutions / community agencies. Training is short: five years on from medical school for psychiatry. Clinical accountability is limited. There is no secondary care like in the UK. Patients with ID have access to generic primary care and tertiary care services. There is a gap, both in access to those generic services and to specialist ID care and support within generic and community settings, causing desperate physicians to turn to antipsychotics in the management of behaviours that challenge. It is not uncommon to see people with ID on 3 antipsychotics.

CAMH is tertiary care, providing consultations and an inpatient service for adults with ID. In Canada, there is no subspeciality in Intellectual Disability (ID) Psychiatry. Care is provided by clinicians with an interest in neurodevelopmental psychiatry, many with a Child & Adolescent speciality background, and trained outside Canada. I shadowed Dr Pushpal Desarkar, a former UK CAMHS psychiatrist, whose special research interest is the plasticity of the brain in ASD, in his weekly referrals team meeting. I witnessed challenges not dissimilar to those in the UK, namely the additional gap that exists for people with ASD and without ID, and the numbers seeking diagnostic assessments.



Dr Elspeth Bradley trained at the Maudsley and St George's in ID Psychiatry, and needs no introduction. She emigrated to Canada 30 years ago. She delivers a wide range of services, from Autism diagnostic assessments using Disco, to EMDR therapy. She has been working towards healthcare improvement for people with ID in Ontario for the past 30 years, including with Dr Yona Lunsky on the development of Canadian primary care guidelines and associated tools. She is an indefatigable publisher on issues of ID and healthcare. She has developed the HELP flowchart which is a wonderful tool to all healthcare providers caring for people with ID. She is a highly valued mentor.



Dr Yona Lunsky has collaborated with Dr Bradley for many years. She looks up to the UK for research and guidelines. She was aware of new NICE guidance and STOMP the same day as I was, on the ID Psychiatry training programme. She is a highly regarded and published clinician with a commitment to parity of care for people with ID in Canada. I was lucky to spend time in her department. We thought of comparing Canadian psychiatry residents, who do not benefit from mandatory clinical exposure in ID, with their UK counterparts. Dr Lunsky admires the UK system of community learning disability teams. She is heavily involved in social media and initiatives to raise awareness of and lower stigma towards ID.

The HCARDD programme, led by Dr Lunsky, has been studying the health and health care of over 66,000 adults with developmental disabilities in Ontario since 2010. Toolkits now exist to assist clinicians, primary carers and emergency care providers to improve their practices with ID patients. These toolkits include clinician tip sheets, patient handouts, information on local resources, and step by step instructions on how to implement changes.



Dr Kerry Boyd is a community clinician and teacher. She is committed to raising awareness of issues faced by patients with ID, and has worked closely with both Dr Lunsky and Dr Bradley. She has received funding to further the cause of ID through the

Curriculum of Caring website, with the active participation of patients with ID - this showcases the HELP toolkit. The Curriculum of Caring website has helpful videos to educate and challenge care providers into patient-centred care. She is an inspiring psychiatrist, at times battling with the odds in order to make patients with ID the highest priority in Ontario health. In the absence of support from authorities in the form of continued funding, social care and legislation, it can be a dis-spiriting enterprise, but her work carries on. She is currently the lead ID psychiatrist at Bethesda, an inpatient unit for patients with ID and challenging behaviour and/or mental illness, funded by the voluntary sector. The lack of robust social and community care provision makes discharge a challenge.

Although the model of care appears to have more gaps than that of the UK, I was struck by the quality of materials, primary care guidelines, tools, videos, and commitment of Drs Bradley, Lunskey and Boyd, in a country where there is no specialised training scheme. As a result of my travel fellowship, I have done a survey of Maudsley trainees to ascertain their knowledge and confidence in caring for patients with ID, I have adopted the HELP toolkit into my KCL lecture: Behaviour is Communication – an Introduction to ID Psychiatry, with the consent of Dr Bradley, and I have trained in EMDR. I have hopes that the HELP toolkit will be more widely adopted to benefit patient care in the UK: as an app to benefit medical students and junior doctors, perhaps?

## References

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H-CARDD: [https://www.youtube.com/watch?v=laD\\_1NbXKQE](https://www.youtube.com/watch?v=laD_1NbXKQE)  
Primary Care Guidelines: <http://www.cfp.ca/content/cfp/64/4/254.full.pdf>. Latest revision 2018 <http://ddprimarycare.surreyplace.ca/guidelines/guidelines-about/>.  
Section 3 of these guidelines: Mental Health and Behaviour <http://www.cfp.ca/content/64/4/254> Tools (being updated): <http://ddprimarycare.surreyplace.ca/tools/> and <http://ddprimarycare.surreyplace.ca/tools/mental-health/>  
HELP for behaviour that challenges: <http://oadd.org/wp-content/uploads/2016/12/41023-JoDD-22-2-v10f-101-120-Bradley-and-Korossy.pdf> also [http://www.cfp.ca/content/64/Suppl\\_2/S23.full](http://www.cfp.ca/content/64/Suppl_2/S23.full)  
HELP article lead by a family physician: [http://www.cfp.ca/content/64/Suppl\\_2/S23/tab-article-info](http://www.cfp.ca/content/64/Suppl_2/S23/tab-article-info)  
HELP flowchart: [https://machealth.ca/programs/curriculum\\_of\\_caring/m/mediagallery/2094](https://machealth.ca/programs/curriculum_of_caring/m/mediagallery/2094)  
Curriculum of Caring: [https://machealth.ca/programs/curriculum\\_of\\_caring/](https://machealth.ca/programs/curriculum_of_caring/)

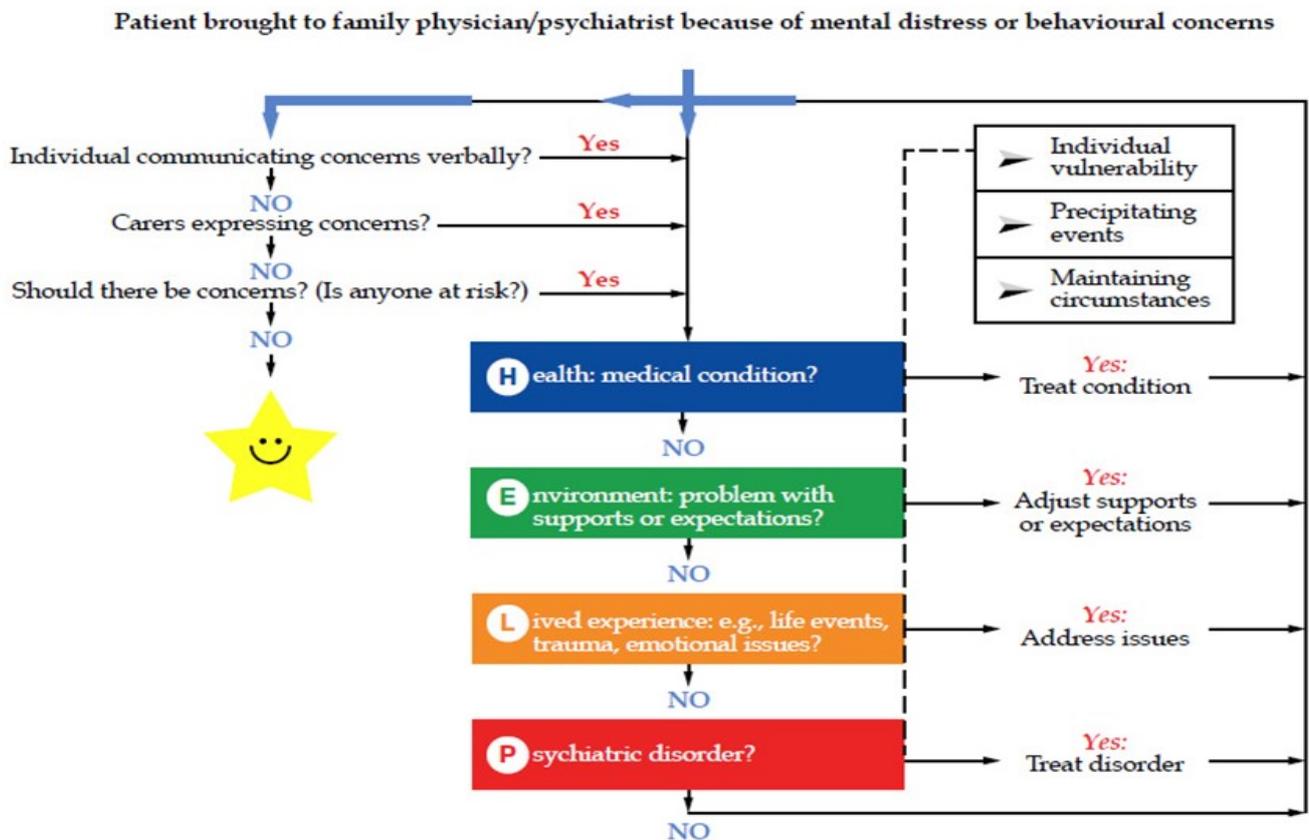


Figure 1. Understanding behaviours that challenge. A guide to assessment and treatment

Reproduced from Bradley, E. & Korossy, M. (2015). Chapter 5: Behaviour problems. In M. Woodbury-Smith (Ed.), *Clinical topics in disorders of intellectual development* (pp. 72–112). London, UK: Royal College of Psychiatrists Publications. copyright© Elspeth Bradley, 2014.



# Psychiatric Trainee Committee: ID perspective

**Dr Catherine Walton**

*Wales Deanery*

*National Higher Trainee Co- Representative,  
ID Faculty RCPsych*



I first heard of the 'PTC' (Psychiatric Trainee Committee) purely through chance. I had happily trained in South Wales for a number of years, had a couple of kids, done a few exams, dealt with a few trainee and rota issues at a local level, and thought of the Royal College as no more than a nice building to go collect my RCPsych certificate from. I then started Speciality Training in ID psychiatry at the end of 2016.

One of the positives of Specialty Training was that I stayed in one place whilst Core Trainees rotated through. This gave me the opportunity to meet and work with a diverse group of individuals - all of whom have had something new and interesting to offer. One of these trainees was Chantelle Wiseman, and over lunch she started to talk to me about her role in the 'PTC'. 'What was this 'PTC' that she was talking about?' I wondered 'And why hadn't I heard about it?'

Having a rather inquisitive nature I looked into the role of the PTC with interest. It concerned me that if one trainee had had their head in the sand (namely me), were there more? Or was this a weakness of the PTC itself? I decided to put myself forward for election, feeling not only that becoming a spokesperson for trainees and training issues would be a great opportunity, but overriding that was the importance I felt of raising the profile of the PTC in South Wales. I was successfully elected as a co-opted member for one year.

I in fact discovered that the PTC is a network of highly motivated and enthusiastic individuals. The elected members attend 2 national meetings per year, have access to a further 2 digital meetings annually, and then will represent psychiatry trainees on another College committee. In the Devolved Nations there are further Executive and local committees to commit to. The committee communicate constantly via a networking application and discussions / topics for debate fly back and forth.

An example of the work that transgresses from local to National platforms include the 'Supported and Valued' (Till et al, 2017) project which utilised local PTC representatives to run focus groups throughout the country in order to estab-

lish the issues facing trainees in psychiatry currently.

Through this, and changes to the junior doctor contract, was borne the idea of 'Enhanced Junior Doctor Forums'. This has been particularly successful in South Wales where the PTC representatives now run at least three forums per year. This is an opportunity for trainees to feedback concerns they have regarding local training issues to the appropriate person, face-to face (See Wiseman et al, 2018 for further detail).

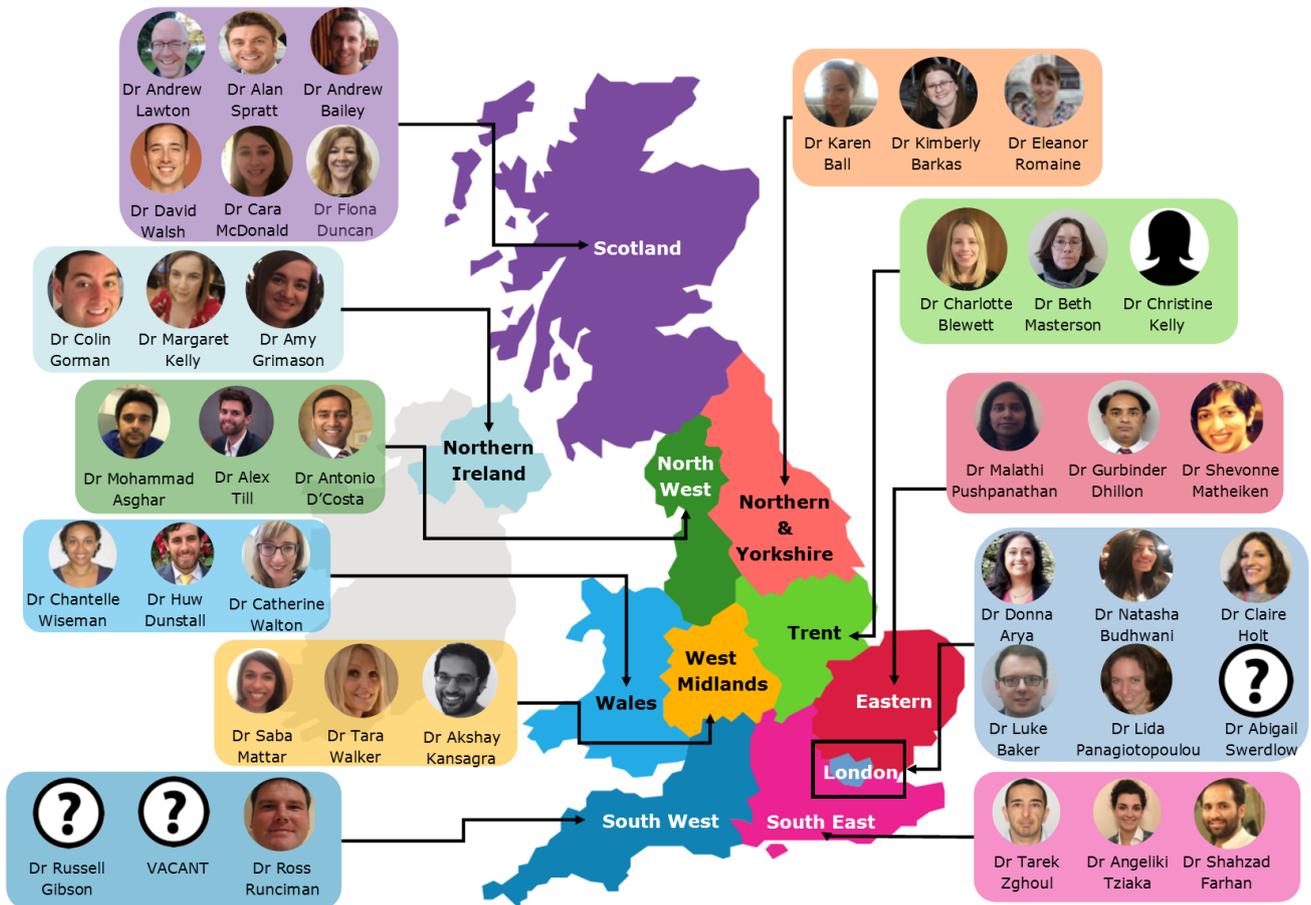
In Wales we have been able to raise local training concerns at both a Deanery and Wales Executive level. The forums have also served as a means of communication around changes in CASC exam marking and some changes to recruitment. They have served as a great way to raise the profile of the PTC in Wales. We have linked in with West and North Wales, either by video link or holding forums in geographically varied areas. There has been an element of fun involved too - with forums invariably being followed up by a trainee social event.

Each of the PTC representatives also links in with another committee within the College, and acts as a representative. As the PTC representative to the ID Executive I have become involved in supporting the ID trainee representatives in local training issues. In the main this has involved signposting and utilising links and contacts within the PTC network to try to offer support. The contact with the ID Executive Committee proved invaluable when I successfully stood for election as an ID trainee representative. Myself and Fionnuala Williams are now working toward improved links between the local ID representatives at Deanery level and the ID Executive. This builds upon the positive experience I had as regards the National Network of PTC representatives over the past year. I am currently trying to link in with all local ID trainee representatives - therefore if you are one and haven't had an email from me - please do get in touch. We also aim to have an ID trainee feedback forum at both the ID Faculty Residential meeting in October and the ID trainee conference in November 2018. Any training concerns or trainee related issues can then be fed back to the ID Executive.

Given my own personal experience prior to 2017 of a complete ignorance of the PTC I hope this article will serve to enlighten any other readers. I also hope it will remind trainees and supervisors of the PTC's existence, the supportive role it can play in trainee issues, and the enormous opportunity that it can be for a junior doctor. If your trainee has not heard of it, then this may be the time to let them know!

Till, A., Millard, K., Tovey, M., Bailey, A., Evans, C., Howson, S, Thom, V (2017). *Supported and valued? A trainee-led review into morale and training within psychiatry*. Psychiatric Trainees' Committee, Royal College of Psychiatrists, UK.

Wiseman C, Romaine E, Till A (2018) *Enhanced Junior Doctor Forums: An implementation guide*. Psychiatric Trainees' Committee, Royal College of Psychiatrists, UK



In case you missed it: Social Media

Jill Bradshaw @TizardCentre says women with @Autism often misdiagnosed with language delay, anxiety and eating disorders and current diagnostic assessments may not always be suitable for women

Dr Ian Hall @IanHallPsych

We looking at how adults with difficulties with capacity and communication are included within the ethical frameworks for research. Funded by @NuffieldFound and led by the fantastic @BunningKaren.

Prof Peter Langdon @p\_langdon



## Job satisfaction in intellectual disabilities- UK based ID faculty cohort survey

**Dr Niyati Sachdeva,**

**Dr Pru Allington-Smith**

*(NS) Consultant Psychiatrist, West Midlands*

*(P A-5) Retired CAMHS ID Consultant psychiatrist*



Recruitment and retention in psychiatry, and more so in Intellectual disability, is a matter of national concern at the present time<sup>1,2</sup>. In an attempt to aid recruitment towards our speciality, we designed a job satisfaction survey for Consultants working in ID, the results of which could be useful to project to medical students, foundation year doctors and core trainees, whilst early on their careers. It is hoped that job satisfaction results would be influential in attracting young doctors towards choosing to work in Intellectual disabilities.

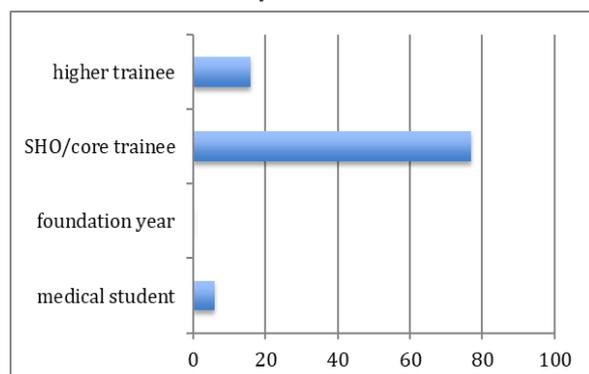
The survey consisted of 10 questions designed on 'Survey Monkey'. The faculty office of Intellectual disabilities at Royal College of Psychiatry was requested to mail the survey to all Consultants registered with them. However, this office does not hold a separate list for Consultants, and hence it was agreed that the survey be posted to all the faculty members. A total of 100 responses were received.

### **Analyses of the results:**

#### **1. How long have you been a Consultant?**

51% of the respondents had been working in ID for more than 10 years, 20% less than 10 but more than 5 years, 22% for more than 5 but less than 10 years and the remaining less than 5 years. These results are a reflection of the stability that this speciality offers, as most members of the faculty have been working in this field for more than 10 years.

#### **2. What level of training were you at when you decided to do intellectual disability?**

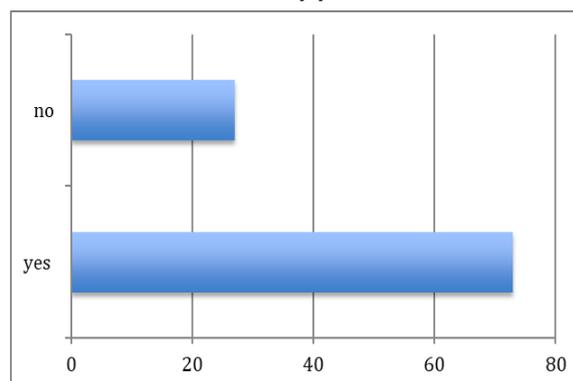


The results reflect that most doctors who chose to work in intellectual disabilities as a career, decided to do it after having the opportunity to be exposed to this speciality in their core training. At present, the number of trainees who get this choice of working in intellectual disabilities are very small. Hence, an awareness of this speciality early on their careers in foundation years and medical school apart from core training may have a beneficial effect on recruitment.

#### **3. Did you join, as it was easier to get into?**

83 % of respondents said no to this question, while only 17% replied yes. Hence, it probably implies that most respondents developed an interest in this area possibly after an exposure to work with people with an intellectual disability, rather than choosing it because it was relatively easier to get in.

#### **4. Was intellectual disability your first choice?**



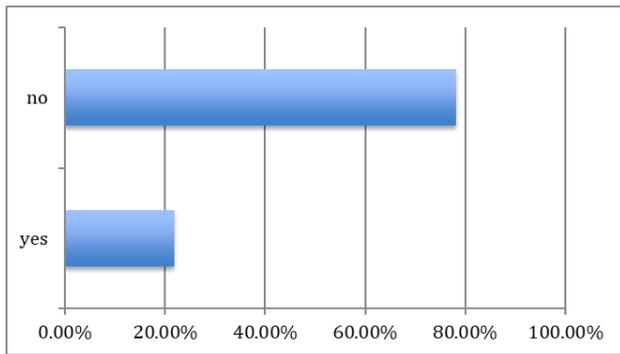
73% of the respondents said this was their first choice, which again implies, the desire to choose it as a career rather than it being relatively easier to get in.

The opportunity to work in well knit multidisciplinary teams, being able to have a positive working relationship with patients and their families/carers may be contributors to this decision.

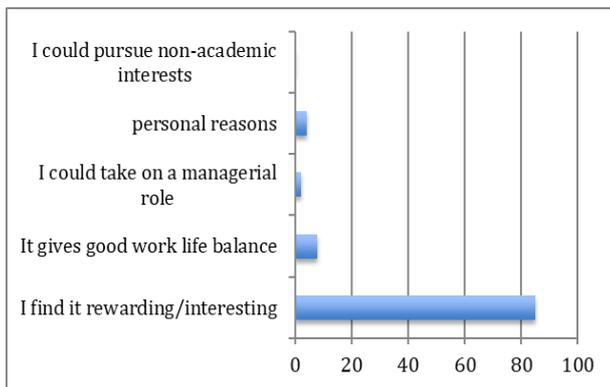
#### **5. If not, did you fall into it by accident?**

27 respondents skipped this question. 57 said no to this question, while 16 said yes they fell into it by accident. The small number of people who fell into it by accident, may not have had opportunity to work in this field before, but once they worked in this speciality, they chose to work in it long term, and possibly find it rewarding.

**6. Do you now regret working in Intellectual Disability?**

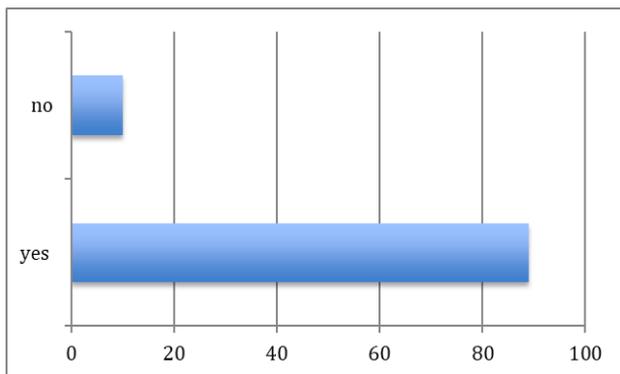


**7. What were your reasons for joining Intellectual Disability?**



The response to the above two questions is highly significant, as nearly 80% of psychiatrists in this speciality have no regrets choosing it as a long term career, rather they find it rewarding/interesting. Budding doctors would benefit from this information.

**8. Did you get a consultant job in the deanery of your choice?**

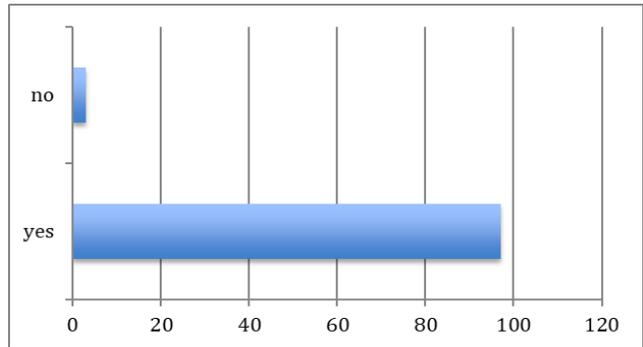


This response may again be quite significant when making career choices, as staying close to family, or being able to find a job in the same deanery as your partner may be useful information for young doctors many of them are also parents with young children.

**9. After how long?**

87.5% of respondents said they could get a job within 1 year, whilst only 4% had to wait more than 2 years.

**10. Would you recommend it as a career choice to trainee psychiatrists?**



**Conclusions:**

The survey was well received and attracted 100 responses from members of the Intellectual disability faculty across the UK. Hence the results can be taken seriously.

Intellectual disability is a rewarding career as suggested by the results of the survey, where 84% of the respondents hold this view. This view should be highlighted at events promoting our speciality.

Most respondents chose to work in this field early on in their careers, nearly 80% whilst they were in SHO/core training. This reflects that the vast majority of people seem to decide on it as a career only once they have experienced a job in ID. At present there is concern that fewer trainees in psychiatry are doing ID in their basic training schemes which needs to be addressed. Promotion of this branch of psychiatry at career fairs in schools, colleges' universities could be beneficial in enhancing recruitment.

One could also argue that this branch of psychiatry offers the advantage of better life work balance, fewer emergencies and quieter on-calls. There is relatively less patient turnover compared to other sub-specialities in psychiatry like general adult psychiatry. Psychiatry in general, is often viewed as unscientific and conceptually weak, compared to other specialities in medicine, but intellectual disability should be promoted to budding doctors as a branch within psychiatry which is very stimulating and offers the specialism/interface between neurology and psychiatry.

The results from the survey show most of them found a Consultant job straightaway in the Deanery of their choice within a year. Again, this a finding which may be useful at promoting our speciality. Most people said that they do not regret their decision and 97% recommended it to trainees as a career choice. This reflects the high levels of job satisfaction that working as a Consultant in Intellectual disabilities offers, something that would be useful to share with future psychiatrists.

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## Bridging the gap – primary and secondary care of those with an intellectual disability

**Dr Archana Anandaram**

[@ArchieA86](#)



*GP Clinical Fellow in ID, Coventry and Warwickshire Partnership Trust*

### Who Am I

Having qualified as a GP in August 2017, I embarked on developing my interest in Intellectual Disabilities (ID). Working with people with ID can be challenging, but ultimately extremely rewarding. Through my foundation years and specialist training I came across so many wonderful families that working towards a specialist interest in ID was an easy decision.

I was fortunate to be in the right place at the right time. A few hopeful emails turned into a one-year clinical fellowship within the ID services of Coventry and Warwickshire Partnership Trust (CWPT) and I was lucky enough to start in January 2018.

The role involves two days working as a GP, two clinical days within the ID Services under the supervision of Dr Ashok Roy, and one academic day with Health Education England (HEE) working on projects to develop the partnership between primary care and specialist services.

### The Gap

Working as a GP, it has been clear to me from the outset that ID is not an area that GPs feel particularly confident or experienced in. Why would they with the minimal training and exposure through the GP training scheme?

This would be unbelievable to a lay person when you consider that primary care is where a large majority of our ID population present and are managed. The association between ID and physical health comorbidities are no secret which also adds to the incomprehensible nature of the gulf between primary care and specialists in ID.

Ultimately, the most important thing is to support each other so our patients can receive the best possible care. GP services are unfortunately not designed for those with ID. 10-minute appointments and time pressures are always a challenge along with automated systems for bookings, investigations etc. which were introduced to increase efficiency. Although reasonable adjustments are being made nationwide, GPs still face numerous barriers to being able to implement these freely.

Transforming care has also led to an increase in number and complexity of community patients in general, with more responsibility and focus of care being within the hands of the GP. Therefore, joint working between ID services and Primary care needs to be as seamless as possible so that patients receive the best possible care.

GPs need to feel supported by specialists to manage this cohort effectively in the community, to reduce the pressure of referrals to specialist services. Likewise, specialist services need to utilize the expertise of primary care with chronic physical and mental health comorbidities to facilitate safe and effective discharge.

Our patients and their carers rightfully expect integrated care between primary and secondary care and therefore our services have to be more closely aligned to provide complementary care in a holistic manner.

### What I Do – The clinical stuff

Within our inpatient units I provide general medical reviews and management, an “in house GP” service. With the focus during inpatient stays often being a patient’s mental health and managing challenging behaviours, addressing physical health care may be overlooked. However, physical health is likely to be a contributory factor.

Specialist Nurses in ID often do not have general nursing and physical health care experience. We have provided education and training to the ward teams to enhance physical health care of inpatients.

For those currently admitted to an acute general hospital I also act as a liaison between the medical team and health facilitators within the community ID team. They do an excellent job supporting patients, families and hospitals during difficult times and I am available when they request support or additional advice.

### What I Do – The Quality improvement stuff

Currently I am working on various ways to improve the engagement of GPs within our region with the Annual Health Checks. Providing additional guidance by giving them someone they can easily access with their queries, endeavours to increase the uptake of the health checks, as well as completing the checks more comprehensively.

I also present at local GP teaching events to build confidence in identifying and managing patients with an ID but sharing the message that they can seek support from specialist colleagues when necessary.

The difficulties in accessing National Screening Programs by those with ID compared to the general population has been well publicised and finding ways to increase uptake is an area that I hope to work on with my community colleagues. Engagement with national screening processes will help close the mortality and morbidity gap that exists.

Thank you

*I'd like to thank the whole team at CWPT for welcoming me over the last six months. I've already learnt a lot and look forward to the ongoing work with the team. Dr Roy and the ID community have been extremely helpful and supportive of my role and I hope many more GPs will have the opportunity to work within ID.*

For those further afield reading this – I would love to hear from you if you have any ideas or projects that you think we would be able to support each other with, so please feel free to email me at [anandaram@doctors.org.uk](mailto:anandaram@doctors.org.uk) and get in touch.

Links

CWPT: <https://www.covwarkpt.nhs.uk>

HEE: <https://hee.nhs.uk>

#### The Annual Health Check:

<https://www.nhs.uk/conditions/learning-disabilities/annual-health-checks/>

<https://www.england.nhs.uk/learning-disabilities/improving-health/annual-health-checks/>

<https://www.england.nhs.uk/south/wp-content/uploads/sites/6/2017/03/Final-LD-Template-Summary-1403-V10.pdf>

Making reasonable adjustments to cancer screening: [https://www.ndti.org.uk/uploads/files/IHaL\\_RA\\_-2012\\_-01.pdf](https://www.ndti.org.uk/uploads/files/IHaL_RA_-2012_-01.pdf)

Learning disabilities resource hub:

<https://www.england.nhs.uk/south-east/our-work/info-professionals/learning-disabilities/resources/>



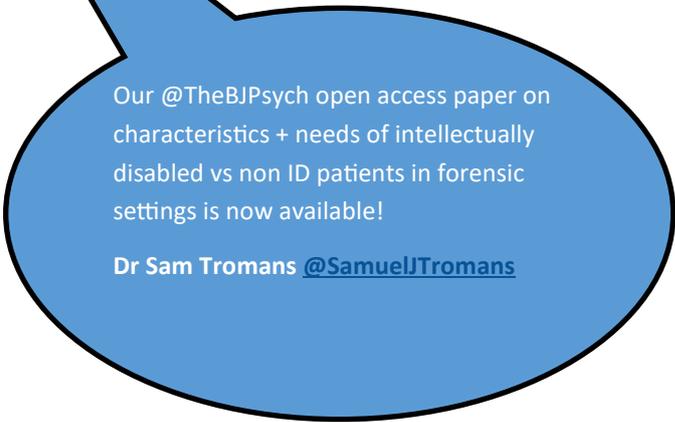
Still a need for #health and social care #integration - "when a mental health and a learning disability team argue over who should take referral of a service user with a "dual diagnosis"...the result is always damaging, distressing, and counterproductive."

Dr Rory Sheehan [@dr\\_rorysheehan](https://twitter.com/dr_rorysheehan)



Delighted to have our Pan European real world study across 45 centres on Perampnamel now published in Epilepsia...amazing piece of work! What is important is that we have a view on ID. Research in ID and AEDs finally taking off but many miles to go.

Dr Rohit Shankar [@haritsa1](https://twitter.com/haritsa1)



Our @TheBJPsych open access paper on characteristics + needs of intellectually disabled vs non ID patients in forensic settings is now available!

Dr Sam Tromans [@SamuelJTromans](https://twitter.com/SamuelJTromans)



# Interview: Tony Holland

Dr Giri Madhavan

[@Dr\\_GiRi\\_PsychID](#)

Higher Trainee

Psychiatry of Intellectual Disabilities

West Midlands Deanery



ited, he emphasised the environmental structures which can be influenced to help people maintain their dignity. He valued being part of the [RCPsych and BPS guidance on people with ID and dementia](#). Interestingly he also highlighted that, with more inclusivity of people with ID to mainstream services, there is an argument that one might expect people with ID and dementia to be served by older adult services.

## Research priorities in ID psychiatry

Tony spoke about how he and his colleagues at the [Cambridge Group](#) deliberately set themselves up as an interdisciplinary group such that they had senior members with sociology, psychology and psychiatry backgrounds and then brought in other expertise. This was a positive way of not just working together but also identifying research priorities.

He described there being some sensitivity attached to research which focussed on the biological aspects of the biopsychosocial approach. However, he emphasized that better understanding of the biological underpinnings of behavioural issues that we as psychiatrists encounter will help in our clinical encounters. An example he illustrated centred around behavioural phenotypes, namely that of Prader-Willi syndrome, with a view to increasing the understanding of the basis for hyperphagia and anger outbursts. He spoke about how we as a profession need to be more confident in approaching aspects of biological models and applying findings from the neurosciences to help our patients. Tony emphasized that whilst behavioural phenotypes were extreme examples, studying them is a good starting point and may also lead to applicability to the general population.

The other big priority Tony highlighted was around the use of restrictions on people's liberty and the interface between clinical practice, social care and the criminal justice system—he emphasized the responsibility we have with such powers to limit people's freedom.

## A typical day

Although Tony has formally retired from NHS clinical work, he continues his registration and is still very involved in several research projects. He continues his involvement with the [Down's Syndrome Association](#) and the [Prader-Willi Syndrome Association](#) and is the president of the [International Prader Willi-Syndrome Organisation](#). On the day of the interview he in fact had already had two conference calls related to these. He still attends academic conferences and is a trustee of [HFT](#) which is a very large social care provider for people with ID.



## About Prof Holland

**Professor Holland is a retired Professor at the University of Cambridge and held the Health Foundation Chair in learning disabilities in the University's Department of Psychiatry. He leads the Cambridge Intellectual and Devel-**

**opmental Disabilities Research Group. He has worked as a psychiatrist in specialist community services for adults with learning disabilities. He has served as an advisor to Government Departments and was one of two advisors to a Parliamentary Scrutiny Committee examining what was then the Mental Capacity Bill.**

## Background

*Many of those in the Faculty will be familiar with Professor Tony Holland from his diverse portfolio of work including many academic and professional achievements. Such achievements have been recognised both inside and outside the field of Intellectual Disability with Tony receiving a CBE in 2015.*

*In mid-August 2018 I interviewed Tony for close to an hour and a half via Skype. He shared some thoughts about his life, both professionally and personally. This proved to be both fascinating and inspiring...*

## Key changes in Dementia services for people with ID

Tony spoke about how many things had changed in his lifetime, not just in dementia, but broadly with ID. Key to this was the increase in life expectancy and a much greater recognition of Downs and dementia. He spoke about the difficult development of structured diagnostic instruments for dementia in ID. Whilst the treatment options are lim-

Tony said that he had taken a lot on before retirement, which he understood many people did, but noted that he was able to focus on these as the pressure of clinical concerns for the past few decades was no longer present.

### **Professional challenges**

Brexit was a key concern of Tony's and he was clear that the European Union was a way of trying to get nations to work together and co-operate rather than compete. He spoke about how he didn't believe an isolationist approach could be better for this country nor did he think the UK could now contribute successfully to the world without being part of Europe. He also spoke of a sadness in thinking back on the many people he had worked with who had come from all over Europe to work in Cambridge, many of who had subsequently married and settled. Funding was a big challenge that Tony noted with Brexit having a significant impact on this.

He also pointed out the differences in recruitment amongst professions, telling me about how only three psychiatrists had completed a PhD with his group but over thirty people with a psychology or neuroscience background had. Definitely food for thought.

### **Greatest influences**

Aside from parents and family, Tony was keen to tell me about a Professor of anatomy, [Professor JZ Young](#). Tony recalled his first week at medical school (University College).

He describes him as wonderfully charismatic (Prof Young was a recipient of the Royal Society gold medal). Tony had completed an anatomy degree supervised by him and found him incredibly inspiring. Not only had they discussed human development but also more philosophical issues relating to us as human beings. He recalls being implanted with a seed that led to his interest in neurology and then in psychiatry. Interestingly, Tony had done general medicine for several years before going into psychiatry.

Another key influence was Chris Green. Tony did voluntary services overseas between school and university in the Seychelles. Tony told me that Chris was Quaker who had left Birmingham to the Seychelles and had spent many years developing social centres there. He described him as having a quiet understanding of life who sadly died whilst Tony was there. Tony continues to stay in touch with Chris's wife (now in her 90s) and daughter.

### **A book should every doctor read**

[East West Street](#) by Philippe Sands.

Tony discussed how this book explores how "Human Rights" and the concepts of "Crimes against Humanity" developed particularly following the Second World War. Tony felt that medical students and doctors of all disciplines should be clear about the principles of human rights and how prejudice can arise and how pervasive it can end up being.

There were a couple of side stories within this book that Tony recounted including the judge at the International Court of Justice, Sir Hersch Lauterpacht, appointing a housekeeper unaware that her brother was the leader of the National Socialist Party, a certain Adolph Hitler.

More close to home, in fact where Tony grew up, was a story about a woman from Norwich, Elsie Tilney, who rescued many Jewish babies and children who were at risk of going to concentration camps at high risk to herself.

### **A film that left an impression**

[The Year of Living Dangerously](#) (1982) directed by Peter Weir starring Mel Gibson.

Tony conveyed to me the film as a moving explanation of Indonesia in the 60s, including moving scenes showing suffering but also exposing the hypocrisy and tensions that exist from overseas powers and the government at the time.

### **When not being a psychiatrist, what do you enjoy?**

Tony described family life being very enjoyable to him. He's taking pleasure in spending time with his first grandchild, a grand-daughter from one of his two sons. His younger sister recently retired as a primary school teacher. He has an active life with his American-born wife who is both an artist and writer. They both enjoy theatre and music, in fact the night before having visited the cinema to watch a broadcast of the opera Vanessa from Glyndebourne. He enjoys spending time in the US, reading and playing the clarinet.

### **When were you happiest?**

Tony spoke of his happy marriage over the last 37 years. Other examples included the time in the Seychelles being the first time away from home and incredibly exciting. Moving from Norfolk to study medicine in London was also life-changing and full of happy memories.

### **Wish list for next five years**

Tony conveyed that ideally there would be agents to prevent dementia as well as promising work on vagal nerve stimulation to help with outbursts that occur in people with PWS.

Tony would like to travel to Burma but has felt with the human rights situation there at present this would be inappropriate. He spoke fondly of his elective period in Thailand, but clearly the link to his father and Burma does still resonate with him.

He also spoke about wishing to support his wife, Bonnie Kemske, with her publishing career. She has recently published a book, [The Tea Bowl: East and West](#).

*Prior to the interview, we did ask Twitter followers if there was anything in particular they wished to hear from Professor Holland.*

## How can we re-ignite the spark of academic ID psychiatry?

(Ashok Roy [@Roy1Ashok](#) )

Tony was clear that bringing the biology back into research was one of the key ways to re-ignite this spark. He spoke about how he didn't think people always realised what an exciting time it is in ID psychiatry research as we now have technologies that allow us to answer questions that we couldn't answer before. He gave examples such as neuroimaging and stem cells. He discussed his own team and his role in addressing the questions that as a clinician he feels need to be addressed. He spoke about engaging with experts in other disciplines such as neuroimaging and genetics can help answer the relevant questions and generate further ideas that keep the spark lit.

## What advice does Prof Holland have for ID psychiatry trainees intending on pursuing a clinical academic career path?

(Sam Tromans [@SamuelJTromans](#) )

Tony discussed that, as psychiatrists, we are unlikely to have all the skills to address some of the important research questions. We may be able perform certain epidemiological research from our training but he highlighted the importance of collaboration and linking in with experts in relevant fields and recognizing that research has to be interdisciplinary. He spoke about his own early recognition of a research question that required answering, namely seeing a patient with Downs and dementia. Being aware as a clinician about research needs to address and then having the confidence to seek collaborations and guidance from people with the skills to help you answer those questions is the best way forward. He suggested that trainees now would do well to study for a PhD- this was a personal regret for him. He felt that a PhD would give credibility amongst peers and other disciplines. Additionally many academic institutions would not now appoint you to an academic post unless you had an MD or PhD.

### Out of the Box

#### If you were not a psychiatrist what other profession would you choose?

A musician /singer/conductor. Tony is currently learning to play the clarinet.

#### Most treasured possession

Tony spoke of his father being in the Army in Burma during the war. Like many soldiers, his father never talked much about this experience but brought back two carved teak figures (*see photograph below*). His father passed away when Tony was in his twenties and this object has a sentimental resonance attached to him.

#### Pet hate

Peanut butter. Interestingly Tony spoke about the cultural differences he notices having an American wife, notably that across the pond Peanut butter and Jam are favoured whereas the British are generally more in favour of Marmite.

#### Greatest extravagance

Tony recounted how he and his brother indulged in a sport car that they shared whilst in London [Tony's identical twin brother, also a doctor, sadly passed away three years ago].

#### Guilty pleasure

Cream Cake.

#### Staying fit

Tony aims to get 10,000 steps a day. He used to row and play squash.





# I am Sam

**Dr Neha Bansal**

**CT2 Trainee**

*West Midlands*



story because Sam can't read the words, or when Sam can't afford to buy Lucy new school shoes and his friends (who also have intellectual disabilities) all pitch in to help him.

Perhaps one of the most heart-wrenching scenes is when Sam is taken to court after being questioned about his ability to parent and arrested for solicitation, with Lucy being detained with monitored visits twice a week. The scene ends with him not fully understanding what has happened and why.

I recently saw the film, "[I am Sam](#)," directed by Jessie Nelson in 2001. Although released nearly 2 decades ago, it was enthusiastically recommended to me by a friend and colleague. Given her enthusiasm and the multi-award winning and Oscar nominee status of the film, I thought I would sit down to watch this "classic."

Then ensue the court proceedings with Michelle Pfeiffer reluctantly agreeing to take his case on 'pro-bono.' Her cut throat attitude and interpersonal issues also begin to resolve, not due to her ongoing "therapy", but by being touched by Sam's warmth, love and kindness and his resilience throughout the case to fight for his daughter, despite his label as being "a retard."

Unfortunately, I was somewhat let down, despite the commendable acting from Sean Penn, the film is filled with contradictions and seems totally unrealistic.

Lucy is taken into foster care and Sam tries desperately hard to abide by the court's rules, find a better job and regain custody of his daughter. The ending seems somewhat abrupt, from the foster care parents fighting to adopt Lucy and then suddenly changing to support Sam and then "they all lived happily ever after."

The film centres around Sam, played by Sean Penn, who has the mental age of a 7 year old and is autistic. He has a child-like innocence and somehow has a daughter with a homeless woman, who then leaves him stranded at a bus stop with a newborn baby. Sam, despite struggling to work at Starbucks, somehow manages to raise a baby.

Given it's been just under two decades since the film was released, I would like to say that general perception of intellectual disability has changed over this time and there is more awareness, however I'm not sure it has. Many still view people with intellectual disability with pity and the film does well to uphold this view and emphasise the stereotypes.

As his daughter, Lucy, gets older, she gains more insight into her father's limitations and we see a kind of parent-child role reversal.

In true Hollywood style, the film has many moments which "pull on your heart strings" for example when Sam's daughter, Lucy, says she doesn't want to read the new bedtime

In case you missed it: Social Media



A strengths based approach for [#challengingbehaviour in ppl w/ #id #START](#)  
Prof Angela Hassiotis [@likahassiotis](#)

# Upcoming conferences

<u>DATE</u>	<u>TITLE</u>	<u>LOCATION</u>	<u>ORGANISATION</u>
<b>MEETINGS</b>			
30 November 2018	Higher Trainee Conference	Double Tree by Hilton Edinburgh City Centre	ID Trainee National Conference Planning Committee
22 January 2019	<a href="#">CESR Training for SAS Doctors</a>	Prescott Street	<a href="#">RCPsych</a>
April 2019	Faculty of Psychiatry of Intellectual Disability Spring Conference	Prescott Street	<a href="#">RCPsych</a>
6 – 9 April 2019	<a href="#">EPA 2019– 27th European Congress of Psychiatry</a>	Warsaw	<a href="#">European Psychiatric Association Congress</a>
23 – 25 May 2019	<a href="#">12th European Congress Mental Health in Intellectual Disability</a>	Palau de Congressos Fira de Barcelona	<a href="#">EAMHID</a>
1-4 July 2019	<a href="#">RCPsych International Congress 2019</a>	Excel, London	<a href="#">RCPsych</a>
August 2019	<a href="#">IASSID World Congress</a>	Glasgow	<a href="#">IASSID</a>

# Upcoming prizes

<u>DATE</u>	<u>TITLE</u>	<u>LOCATION</u>	<u>ELIGIBILITY</u>	<u>PRIZE</u>
<b>PRIZES</b>				
1 December 2018	<a href="#">The Professor Joan Bicknell Medical Student Essay Prize</a>	Presented at the Faculty Spring meeting, usually held in April each year	Eligible: Any medical student in the UK can enter.	<b>Prize: £250</b>  We established this prize to be awarded for an essay written by a medical student about their contact with a person or people with an intellectual disability during the course of their studies.
30 April 2019	<a href="#">The Brian Oliver prize</a>	Presented at the Faculty annual residential meeting., usually held in Autumn each year	Eligible: Applicants must be in an approved UK training scheme working at CT1-ST6 level or within the first 3 years of a Consultant post.	<b>Prize: £500</b>  The prize is awarded for research undertaken in the psychiatry of intellectual disability.

