

# Psychiatry of Intellectual Disability

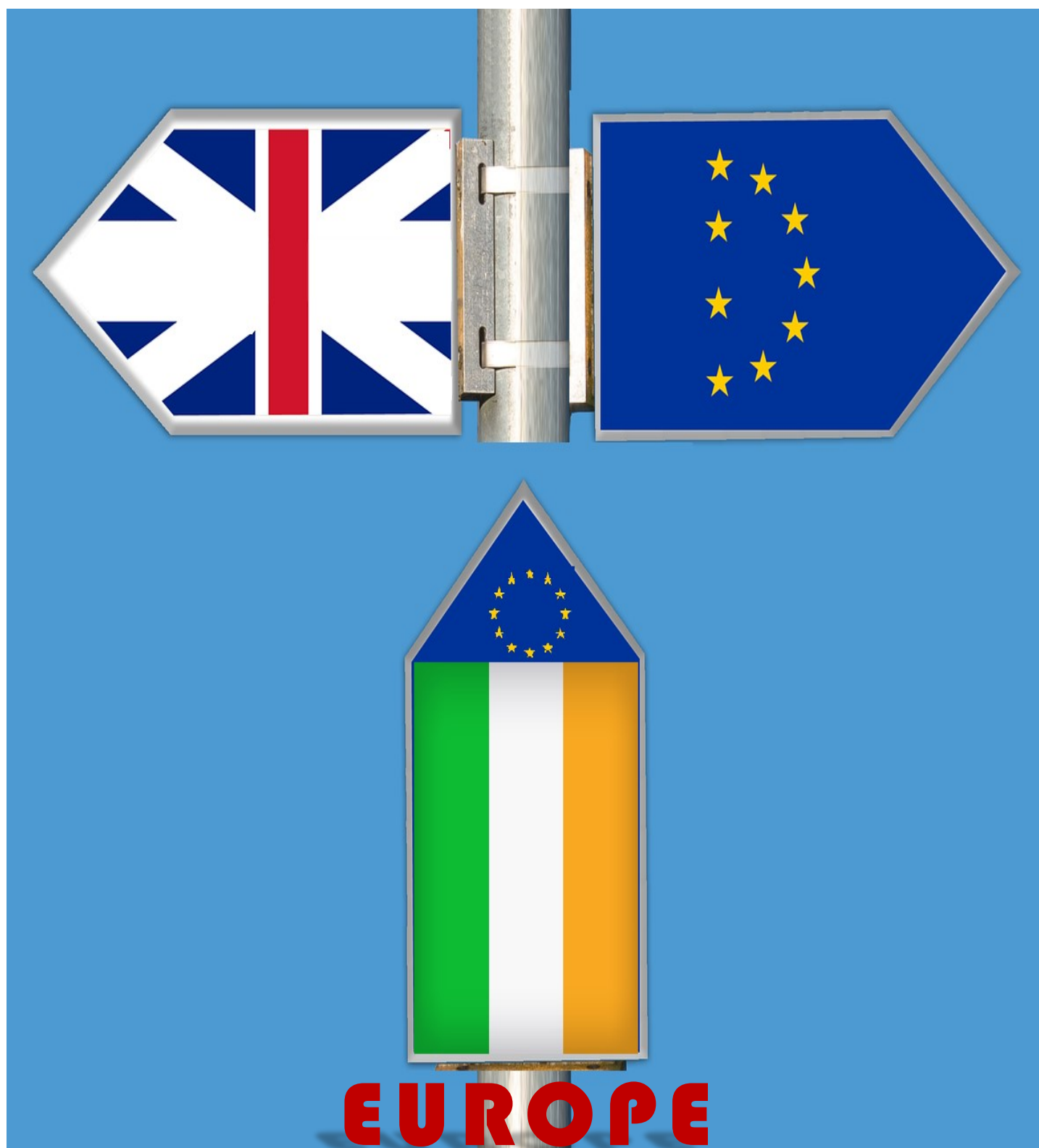
Newsletter of the Faculty of Psychiatry of Intellectual Disability

APRIL 2018 Vol 20, Issue 1



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# Editorial Group

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**Tom Berney**



**Ken Courtenay**



**Elizabeth O'Rourke**



**Giri Madhavan**

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## Europe



*With Brexit just a year away, it feels fitting to have the theme of Europe for this edition of the newsletter with two articles that feature on Europe.*

*Tom has handed over editorial lead to Giri. We are aiming to have regular columns in addition to the featured articles. We are fortunate to have Rachel Steele's regular I-Spy and will be providing regular Prize updates in future. We would encourage readers to contribute their own articles, including reviews of books or films that are related to the field of ID psychiatry. We are also interested in finding out who you would like to be interviewed in future newsletter editions. In fact, if you have any suggestions please feel free to contact us and we'll endeavour to improve the newsletter.*

*As with the previous edition, relevant hyperlinks are interspersed throughout the electronic version.*

*We wish all the outgoing Executive committee members the very best in their future endeavours and thank them for their support with the newsletter.*

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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** or **Kitti Kottasz**, Faculty Committee Manager ([kkottasz@rcpsych.ac.uk](mailto:kkottasz@rcpsych.ac.uk)).

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

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## View from the Chair

**Dr Ashok Roy**

**Chair of ID Faculty**

*Consultant in ID Psychiatry,*

*Coventry and Warwickshire NHS  
Trust*



You will be pleased to see our newsletter which has had a major facelift and has more content than before thanks to the efforts of our editorial team which is now led by Giri Madhavan.

One of our colleagues has faced the fallout from the Connor Sparrowhawk case which has raised difficult questions of the level of responsibility that we take when working in teams and being involved in complex multidisciplinary care plans which we may not be responsible for delivering directly. The case has highlighted the importance of the need for us to remain competent in managing epilepsy in our patients although in some parts of the country this has been led by neurologists. I would refer you to the recently released College Reports (CR 203 and CR 206) to help plan any training needs you may have.

The Faculty work on STOMP has continued to gather momentum and our plans to help in the reduction of overmedication have led to numerous local initiatives. These have included active liaison and support to GPs, development of medication reduction clinics, behavioural clinics and a greater role for pharmacists.

I am happy to provide feedback on an important meeting that NHS England helped to organise which brought together parents and psychiatrists into one room to see how we could learn from the past and work better together in future. Issues that we agreed on included the importance of co-production with regard to training and developing ideas for information sharing and care planning. The event was positive and in some instances cathartic, clearing up misconceptions about each other and agreeing to work together by developing a code of practice for the future. To me this was a significant development given the negative publicity we have received over years, especially with the difficulties encoun-

tered with discharging long stay patients from hospitals in the wake of Winterbourne View.

I would like to congratulate three people in particular. We had a veritable bonanza of Honours in our Faculty with Prof Sally Ann Cooper being conferred an OBE and Rohit Shankar an MBE. Our recently appointed SAC Chair John Russell has been appointed Associate Dean: Curriculum. While this is a loss for our SAC it gives John an opportunity to give greater prominence to ID in the curriculum.

There has been a delay in the publication of the joint report of HEE/ID Faculty/Tizard Centre. We expect it be placed on the HEE website soon. Initial figures suggest that in order to implement the new model of care (Building the Right Support in England) would need an additional 80 – 90 consultants and additional supporting medical staff. While some of these leaders of Intensive Support Teams and Community Forensic Teams will come from hospitals that are closing we will need to train and appoint them in addition to what we had planned for. So let no one tell you that there is a reduced demand for ID Psychiatry!

As this is my last message to you as Chair of the ID Faculty I would like to thank you all for making this an extremely enjoyable role which I have been privileged to have. I have been lucky to have my 4 year term coincide with a number of brilliant people too numerous to name who have done a lot of hard work in keeping the Faculty supportive and relevant to your working lives. Elections are nearly here so please cast your vote and ensure that the future office bearers continue to help you meet the high professional standards demanded of ID psychiatrists

Our Spring Conference is taking place on April 20th at the College. I hope to see you there.

Ashok Roy  
April 2018

# Research Roundup

**Rachel Steele**

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



*Rachel Steele begins the I-Spy Research Series with a review of Palliative Care as well as a round-up of the latest Intellectual Disability research.*

## Palliative care for people with learning disabilities

Many individuals with learning disabilities have a similar life expectancy to the general population (Duc et al., 2017). The planning and provision of palliative care has therefore assumed an increasing importance for people with intellectual disabilities and their families (Tuffrey-Wijne et al., 2007). The modern hospice movement which originated in the 1960s originally focused on cancer patients (Tuffrey-Wijne et al., 2007). While cancer patients still comprise the majority of hospice patients, there is increasing recognition that palliative care providers must provide appropriate care to all people with a terminal illness, irrespective of their diagnosis (Tuffrey-Wijne et al., 2007). There are, however, specific challenges to providing appropriate palliative care to people with learning disabilities. For example, a cornerstone of palliative care is managing pain but assessing pain in people with intellectual disabilities poses problems because of factors such as communication difficulties.

A 2007 systematic review concluded that research relating to the palliative care requirements of people with learning disabilities is limited and that case reports are the most common methods of investigating the issues (Tuffrey-Wijne et al., 2007). A later literature review focused on the subset of children with learning disabilities and medical complexity for whom life expectancy is reduced compared to the general population. It argued that longitudinal child- and family-centred approaches are the best means of ensuring good quality care for the families of these children (Duc et al., 2017).

Given the challenges, and the dearth of research, into the delivery of palliative care for people with intellectual disabilities, '[Top tips guidance](#)' has been released to help reduce

inequality in palliative and end of life care for people with learning disabilities. The guidance has been developed jointly by NHS England and the [Palliative Care for People with Learning Disabilities \(PCPLD\) network](#). It provides tips, resources and good practice examples with the aim of working towards [ambitions for palliative and end of life care](#).

## I-Spy Round-Up

Parents' experiences, and interactions with, health and education services have an important impact on their stress, well-being and adaptation to their child's disability. A qualitative study found that parents desired greater collaboration between themselves and professionals and that they viewed a keyworker as a potential solution to the current system which, they feel, is not child-centred (Ryan and Quinlan, 2018).

A recent systematic review investigated admissions for physical health conditions amongst people with intellectual disabilities compared to the general population. The review concluded that admissions are common and that asthma and diabetes admission data suggests suboptimal primary care management of these conditions compared to the general population (Dunn et al., 2018).

Stress is common amongst professional caregivers of people with intellectual disabilities and may lead to psychological distress with a number of associated adverse outcomes. A recent systematic review concluded that mindfulness-based interventions may, at least in the short-term, aid in the management of distress in these caregivers (O'Donnchadha et al., 2018).

As support workers play a pivotal role in the lives of people with intellectual disabilities, it is important for health professionals to work effectively with them. A systematic review of qualitative research found that professionals can collaborate by providing effective leadership, working in partnership with support workers and recognising the influence of the organisational backdrop (Haines and Brown, 2018).

It has been shown that regular exercise has benefits for physical fitness and psychosocial well-being. A recent study confirmed these findings in relation to men with intellectual disabilities in secure settings who have participated in com-

# Research Roundup

munity football training programmes (Hudson et al., 2018).

Terband et al. (2018) investigated the effectiveness of speech therapy (comprising personalised training in articulation and listening skills) in adults with mild and moderate ID. They found the therapy had benefits for speech intelligibility and receptive vocabulary, irrespective of the degree of ID, hearing loss or ID aetiology.

While the use of Internet and mobile phone technologies is of burgeoning research interest, few studies have explored their use by young adults with ID. Jenaro et al. (2018) found that young adults with ID make greater use of these technologies for social or recreational, than educational, purposes and that they show greater excessive use than their general population peers.

Wolfe et al. (2018) explored the views of UK psychiatrists in genetic testing. They found that, compared to child and adolescent psychiatrists, intellectual disability psychiatrists made greater use of genetic tests and genetic services and were overall more confident in the genetic testing process.

It is important for people with ID to have employment opportunities to combat social exclusion. A recent systematic review found high job satisfaction in people with ID and that predictors of job satisfaction are similar to the general population (Kocman and Weber, 2018).

CBT is increasingly being adapted for people with ID but it is unclear whether cognitive issues can impact on its delivery via computer methods. A recent systematic review concluded that research findings relating to emotion recognition, cognitive mediation, discrimination between feelings, thoughts and behaviours, linking events and emotions impact on the delivery of CBT (Cooney et al., 2018).

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# The Higher Trainee Conference

**Dr Giri Madhavan**



*Higher trainee representative West Midlands Deanery*

*This year we saw the higher trainee conference hosted by the Health Education North West Trainees in Manchester on a crisp November [Black] Friday. There was a great turnout of 70 delegates and it was fantastic to see not just so many higher trainees, but also several core trainees, specialty doctors and consultants. In fact I met several allied health professionals and a postgraduate psychologist as I arrived. There was certainly a buzz in the air from the start and it was great to feel the event was inclusive.*

The day started with the first keynote address from **Dr Peter Mason** on ADHD and ID. We learnt about Dr Mason's ADHD assessment service and how he became an expert in the field by interest and circumstances. It was motivating to hear a real story of medical leadership stemming from interest and serendipity, which challenged some of the ideas of being taught leadership that have recently permeated the mainstream health education agenda. The QbTest description and images drew particular interest, and it was fascinating to hear the logical yet paradoxical idea that in spite of the stimulatory effect of methylphenidate, it could improve sleep as the mind of the patient becomes more focused. The advantages of lisdexamfetamine as a treatment (especially being non-injectable (even if boiled in Coca-Cola (yes, really...))), the concept of atomoxetine mediating permanent brain alterations, as well as Dr Mason's experience of seeing large amounts of comorbidity of bipolar disorder with ADHD and the advice to prioritize treatment of the bipolar disorder before commencing ADHD treatment, meant the audience were keen to ask many questions. Further interest was generated by Dr Mason's irreverent approach to a few managers in the audience with regard to commissioning and a waiting list, unless I heard wrong, of 25 years! "Entertaining" and "informative" were a few comments I gathered from delegates in the break.

**Professor Bhaumik's** keynote address followed. This was a well-received overview on managing challenging behaviour in ID. As this is such a key part of our work, it was a huge privilege to have such an esteemed speaker providing a concise and practical approach, with references to the evidence-base throughout his address. Revision of the Mace and Mauk subtypes as well as a practical flowchart of the topic were eagerly replicated on delegates' notepads and iPads. Prof Bhaumik summarised the biological theories on self-injurious behaviour and walked us stepwise through the concepts of Differential Reinforcement of Other Behaviours (DRO) and Differential Reinforcement of Incompatible Behaviors (DRI) with clinical examples which helped to reinforce these. Needless to say, the delegates were captivated by the talk and the discussion.



In the ensuing refreshment break conversation was flowing, networks were blossoming, a few pens picked up from the various sponsor stands and both pastries and posters were being digested, gastrically and mentally respectively (although I could sense some doing the latter to the former).

Three concurrent sessions then took place. **Dr Mark Lovell** (@dr\_marklovell) presented a session on differential diagnosis and co-morbidity in ID, ADHD and ASD from a clinical perspective which gave attendees key insights and nuggets to mull over. **Dr Neel Halder** presented a session on 10 easy steps to successful medical publications. Attendees left with

solid tips to maximize this important part of training (and beyond). Dr Halder's paper (Advances in Psychiatric Treatment, 17 (2011): 150-157) was suggested to me by an attendee as being a good place to refer to for those interested in publishing, as understanding the peer review process helps give an insight into how to make a paper more likely to be publishable. I have since read this and highly recommend this.

I attended **Dr Czarina Kirk's** riveting discussion of neuropsychiatric conditions in the Criminal Justice System. Dr Kirk presented a case vignette of a patient with post-ictal psychosis. This was the stem from which so much learning and discussion branched out. Although rare, it was fascinating to learn about the overlap between epilepsy and psychosis as well as the complex interplay of the psychiatrist in the legal setting. We were provided with further information on the case and given the opportunity to discuss this in small groups. This was highly interactive and when we were polled about whether we thought the patient was fit to plead in court, the absence of universal agreement resulted in an interesting discussion. Dr Kirk reminded us of key legal concepts such as Coke's *actus rea* and *mens rea*, M'Naughten's rules and introduced the less familiar Bratty v A-G for N. Ireland [1963] AC 386 and the Logsdail and Toone Diagnostic Criteria for Postictal Psychosis.

The afternoon sessions followed an enjoyable lunch, with the usual conference balancing act of plates, delegate packs and drinks. There was the hum of conversation although I did spot a few people picking up their Black Friday deals, which I imagine had been on hold all morning.



The first keynote in the afternoon was an entertaining and slightly quirky whistlestop by **Dr Ross Overshott** on the history of mainstream movies representing mental health followed by a focus on films with ID. There was a mixture of horror and amusement when clips were shown of early Hollywood's sil-

ver screen representation of mental illness as well as some more recent features. [Hint- film reviews as future newsletter articles for aspiring authors]. Interestingly, it turned out Forrest Gump wouldn't be classed as having an ID as the film reveals his IQ of 75. Another revelation was not only that Michael Douglas was the producer of "One Flew over the Cuckoo's Nest", but also that he was reported to have described none of the real patients [in the institution] "looking mad enough" when they were recruiting extras for the film. . It wasn't all negative portrayals, and Dr Overshott was clear to point out how much the industry has matured over the years and went through a few respectable depictions. Certainly, we would all do well to reflect on the portrayal of our profession to the public by such powerful forces.

**Dr Jean O'Hara** followed with a keynote on Transforming Care and described the progress on the NHSE Learning Disabilities Programme (2016 – 2019). We were reminded about how the program of Transforming care was not just about bed numbers but about "transforming lives". Dr O'Hara stressed the co-production values with users and families, illustrating this with NHS England practising what it preaches by employing five staff members with an ID. It sounded like these were integral members of the team, rather than a tokenistic gesture for PR literature. CTRs as a described as a disruptive innovation and Dr O'Hara emphasized about how disruption can help people think differently. We were shown some of the data on reduction of lengths of stay and how many people have now been discharged into the community. Public Health England were commissioned to analyse 30 million patient records and additionally templates are being added to the GP annual health check with a target of 75% completion of these by 2020 (currently the best GP practices in the samples are only managing 50%). We were given a brief overview of "always events" and Dr O'Hara was positive about the work with NHS improvement who work directly with commissioners. Clearly with so many changes, there were bound to be questions from the audience. These included the role of the private sector and the changing skill mix of the workforce with the movement into the community.

After a short break for refreshments and poster viewing, I joined the platform with my fellow **National representatives** (Elizabeth and Nadia) to talk about what we have done in post so far including work on training, promoting interest in ID psychiatry in the context of the overall recruitment crisis in psychiatry and of course, the newsletter. We also had a few minutes to gauge some views about experiences in training. It was clear there is still variation across the UK and we are encouraging trainee members to feed back to us directly so we can raise concerns and share positive practice with the Col-



lege.

We also encouraged fellow trainees to consider putting themselves forward for the Higher Trainee Representative role for next year as we would all agree it has been a fascinating experience and has certainly helped us develop insight into the college and national agenda. Trainees were also encouraged to consider writing for the newsletter.

The final afternoon current sessions were again split into threes. I chose to join **Dr Arun Chidambaram** in his discussion of the Forensic ID service. It was fascinating to hear about the use of design thinking methodology in violence reduction leading to an 87% reduction in staff injuries. Dr Chidambaram presented a history and description of more recent changes to the Calderstones unit. In addition he illustrated several risk assessment tools and some of the difficulties faced by professionals in this complex patient group when it comes to assessment and treatment. I was told that **Dr Ruth Bevan's** session on Gender Dysphoria, Autism and ID was fascinating with a high degree of interactivity. It is clearly a topic that is becoming more and more familiar to practitioners and therefore I would encourage readers to refer to Dr Bevan's article from a previous newsletter (<http://www.rcpsych.ac.uk/workinpsychiatry/faculties/intellectualdisability/newsletters/newsletterjanuary2016/genderdysphoriaandintellect.aspx>).

**Dr Mahesh Odiyoor** presented a session on developing future leaders and gave a thoroughly interactive discussion with realistic and practical tips on how trainees can get involved in leadership. All of this was done in the context of the Medical Leadership Competency Framework and therefore was easily accessible to many of us trainees who are very familiar with this. The presentation was described as inspiring and being one that enthused its participants to leave the day with plans for action.

The finale of the day was the poster prize presentation. Dr Lovell spoke about the difficulty the judges had in selecting the prizewinning poster as there was such high quality in the 17 that had been submitted. Therefore the judges decided on awarding a category of highly commended posters. These were awarded to Jo Davies and Eleanor Hughes. The prize winner was Dr Shilpee Soren.

Many congratulations to her and those commended.

Many thanks to the **committee members** from Health Education Northwest for organising the 2017 ID Higher Trainee Conference. It was highly enjoyable and informative, with much to mull over on the 17:27 rush hour train back to West Midlands. Let's just say I'm glad I booked a seat with a tray to tidy up my notes for this article as there was little room to move for those who had not!



Congratulations to **Glasgow** for their election to hosting next year's trainee conference (details to follow). See you there and do encourage any aspiring ID psychiatrists as well as current trainees to consider attending.



# The ID SAC

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**Dr John Russell**

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*Chair of the ID Specialty Advisory Committee*

Firstly, I want to thank, as well acknowledge the work of, my predecessor Dr Asit Biswas, Chair of the ID Faculty Education and Curriculum Committee.

The College FECCs changed into SACs in 2017 and we held our first SAC on 11th September 2017, followed by a second meeting on 2nd February 2018 at the College. We discussed the terms of reference as well as roles and allocated these as appropriate. Those attending (in person or via the phone) included Eileen McNamara, Deval Bagalkote, Mary Barrett, Nadia Awan, Elizabeth O'Rourke, Khuljit Bhogal, Gill Bell, Ian Hall, Geoff Marston, and Pancho Ghatak. Tony Roche is our Curricula and Quality Manager.

Remit:

### **A) Curriculum – curriculum review and development:**

All College curricula are to be re-mapped to the GMC Generic Professional Capabilities by 2020. In the meantime no changes will be made to the ID curriculum or WPBA numbers pending the changes. The only exception to this is regarding Emergency Care Competencies. The suggestions for ID, (made by a working group for all curricula) will be adopted and incorporated in the near future.

We have also been in discussion with relevant others, in preparing for the remapping process, to update competencies in the management of epilepsy in those with ID, diagnosis and management of ASD, psychotherapy competencies, leadership skills, community ID Forensic skills and management of inpatients amongst others. We need to be mindful of STOMP and the implications for training to achieve this.

### **B) Assessment – assessment engagement and development:**

It is likely that WPBAs will change in the future to 'Supervised Learning Events' – these are available to be used currently in the Portfolio but do not count toward the numbers of WPBAs required for ARCPs.

Of note, as part of the ST4 recruitment process, we also hope to begin to have participation from actors with ID in the clinical communication station in the future.

### **C) Workforce – to gain a national picture of posts and programmes, recruitment successes and concerns, other workforce developments:**

In order to try to gather this information we have set up a group e-mail with all the ID ST4-6 TPDs across the UK. An online questionnaire has been sent to all the TPDs and the results will be fed back to the Faculty in the near future. The initial response rate has been good.

### **D) Quality Assurance – for OOP requests/reviews when required and lead on quality analysis:**

The SAC will be represented at the RCPsych QA committee. This scrutinises OOP requests for placements out with the trainee's base School or Deanery region.

The main challenge for our specialty remains recruitment. The SAC hopes however that its ongoing work for the Faculty and College ('Choose Psychiatry') will help with this to ensure high quality consistent training across the UK which may in turn attract future trainees.

Finally 'Shape of Training' has been signed off by all 4 Health ministers across the UK. We are not sure at present how this will develop and what the role of credentialing will be. Watch this space!!

If anyone has any queries though about training please do not hesitate to contact me on [johnrussell@nhs.net](mailto:johnrussell@nhs.net)

# STOMP Survey Report

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**Dr Ken Courtenay**

**Vice- Chair of ID Faculty**

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



## Introduction

STOMP is an initiative to reduce the inappropriate use of psychotropic medication in people with ID and in people with Autism originating from the Transforming Care Programme in Building the Right Support (2015). The STOMP campaign was launched in 2016 by a pledge signed professional bodies. STOMP is an initiative of NHS England and the Faculty considers it relevant to the practice of Psychiatrists in all countries of the UK. The Faculty's pledge describes what the Faculty would do to support its members in STOMP. In 2017 the Faculty conducted a survey of members to ascertain their level of awareness of STOMP and the Faculty's pledge commitments. The survey asked members for suggestions on support they needed to implement STOMP.

## Method

An on-line survey of Faculty members was carried out over a three-week period. The survey consisted of sixteen questions on knowledge of STOMP and resources available to support doctors.

## Findings

Ninety-five responses were received from Consultants (84%), Specialty Doctors (6%), Trainees (9%).

### STOMP

Knowledge of STOMP from Faculty resources was 66% and over 75% have read the Pledge ([hyperlink](#)). 28% had not received information from the College on STOMP. Almost two-thirds of members had received information on STOMP supporting Item 1 of the Faculty Pledge. 59% had used Faculty resources when managing psychotropic medication.

### Practice

In the area of care plans, 82% involve other professionals in developing care plans for people with challenging behaviour. Almost 96% involve carers 'usually' or 'always' in care planning.

### Diagnosis

The most common classification system used was ICD 10 (91%) and 97% communicate with GPs on diagnosis and medication regimens. 48% use HoNOS-LD as their measure and 22% use CGI tool and 37% do not use an outcome measure.

### Medication Review

Medication reviews take place in out-patient clinics, home visits, and using information from carers and family members. The respondents relied on patients and their carers to report on side effects of medication. 37% used a rating scale to assess for side effects.

### Quality Improvement

Members consider STOMP as part of Quality Improvement in their services where 56% had conducted QI on psychotropic medication. A further 21% were interested in using QI methodology in prescribing in their practice. 64% had contributed to the POMH-UK (LD) survey of anti-psychotic prescribing and 90% supported a national prescribing audit of ID teams.

### Training in Autism

Seventy-three (77%) of respondents had completed training in using an Autism assessment tool, the most common tools used were ADOS (55%), ADI-R (45%), and DISCO (33%).

## Discussion

The Faculty of Psychiatry of Intellectual Disability is committed STOMP having developed its Pledge to promote good practice among its members. The purpose of this survey was to gain an impression of current practice among Psychiatrists in ID and of their awareness of STOMP. The survey generated responses from 95 psychiatrists.

Psychiatrists are aware of STOMP and the commitment of the Faculty to it. Over a quarter of respondents had not

received information on STOMP but were aware of the Faculty Pledge.

Over 40% of respondents had not used Faculty resources for example, FR/ID/09 in considering their medication management that are readily available to use and therefore more promotion of Faculty resources to support members is needed.

The survey indicates several areas of good practice among Psychiatrists for example, involving others in developing care plans to manage challenging behaviour that involve prescribing medication, communication with General Practitioners, and using a classification system when making a diagnosis. There is a high level of practice in using assessment tools in Autism in line with Item 3.4 of the Pledge.

Areas for improvement include structured reviews and monitoring of medication using an outcome scale and assessing for the presence of side effects. The Faculty will encourage its members to incorporate in to their practice more objective measures of the effectiveness of prescribing.

The respondents suggested future areas for development by the Faculty in keeping with Item 10 of the Pledge for example, eLearning materials.

Psychiatrists engage in Quality Improvement in their services but the difficulties highlighted included time and support within services to carry out QI activities.

The next steps for the Faculty is to promote a culture of change in the prescribing and monitoring of psychotropic medication:

- Promotion of the Pledge
- Promotion of Faculty resources tailored to specific groups for example, Children and People with Autism
- Maintain awareness among Psychiatrists of STOMP through academic work and practical supportive measures

- The development of resources for example, accessible information, eLearning materials
- Psychiatrists should engage with STOMP through the following steps:
- Maintain good areas of practice
- Use outcome measures in practice and objectively assess for the presence of side effects
- Demonstrate Quality Improvement in prescribing practice in services

## Conclusion

The survey provides good evidence of awareness of STOMP among Psychiatrists. To achieve further change in the culture of prescribing psychotropic medication Psychiatrists are at the forefront of leading change in their services. The Faculty will lead and assist members to promote STOMP in services. This will ultimately be implemented by colleagues providing a multi-disciplinary approach in clinical teams to reduce reliance on psychotropic medication in supporting people with challenging behaviour.

## References

NHSE (2015) Building the Right Support

<https://www.england.nhs.uk/wp-content/uploads/2015/10/ld-nat-imp-plan-oct15.pdf>

STOMP Pledge

[http://www.rcpsych.ac.uk/pdf/STOMP\\_Faculty\\_Psychiatry\\_Intellectual\\_Disability\\_\(002\).pdf](http://www.rcpsych.ac.uk/pdf/STOMP_Faculty_Psychiatry_Intellectual_Disability_(002).pdf)





# The latest ID add-on: Trauma-informed Practice

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**Dr Tom Berney**

**Newsletter Editor**

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*Retired Consultant in ID Psychiatry*



There have been a steady series of substantial changes in the care and education of people with Intellectual Disabilities (ID) over the last thirty years, the overall direction of travel being towards individual autonomy, domestic settings and the encouragement of closer, more stable and sustained relationships. For most, this is still an aspiration as, although more attention is given to family links, service limitations continue to face the individual with a kaleidoscope of personnel and placements. This is on top of a turbulent life where it is not unusual the focus of domestic turmoil involving parental separation or breakdown, drug and alcohol abuse, and violence. Many will have experienced multiple placements, sudden changes to living arrangements, bullying and harassment in school and in the wider community, as well as verbal, physical and sexual abuse. While some have had the resilience to recover from a complicated and turbulent life, most will need a compensatory approach to their care that recognises and acknowledges what they have experienced. This is the essence of a trauma-informed approach and Bowlby's Attachment Theory provides its theoretical underpinning.

A secure attachment, which requires some degree of constitutional sturdiness, as well as a good enough caregiving person or persons, is the starting point of normal development into an independent, confident adult that understands their past and can cope with adversity. On the other hand, deprivation or distortion of early relationships can result in an adult who is disturbed and has difficulty with coping with their current life and relationships. Their presentation will fall into ICD-11's new category of Complex Posttraumatic Disorder and, although it may take a variety of forms, can be similar to the characteristics of those with an innate neurodisability, such as autism or ADHD. Where these innate conditions are already present, they can make the person more vulnerable to the effects of adversity which, in turn, may amplify their innate symptoms. In the end, the extent

of their coexistence may only be clarified by their response to their management.

Central to their management is:

1. A safe and consistent placement where the person can develop long-term relationships and be reasonably confident that they are not going to be moved on, punished or rejected because the system (which includes where they live and those supporting them) cannot cope with their challenging behaviour. This stability requires a combination of physical, emotional and financial security.
2. Understanding the individual's perspective (even though its relationship to reality may appear tenuous) acknowledging it, and giving it due weight: the individual should feel heard and understood. Those supporting the individual need to appreciate the likelihood that they will have experienced trauma and have sufficient counselling skill to hear, understand and help them move on (recognising the fine line between encouraging disclosure and the development of false memories).
3. A training programme that includes staff at all levels as well as families and carers so that their knowledge and skills are sufficient to maintain the previous two points.
4. A number of specialist treatments although, as yet, there is very limited evidence of their effectiveness when adapted for people with ID.

This approach, with its emphasis on relationships, complements the other initiatives in ID, notably community living, inclusion, advocacy and Positive Behaviour Support. It is not new; familiar to children's services in the management of Attachment Disorder, it is only recently that it has become a specific focus in adult ID. However, it is being taken up and developed by services as far apart as Melbourne (1) and New York (2) while Scotland has gone some way towards introducing this component of care across all care services (3). In retrospect, this line of thinking has led to a profound change in the way we think about child care. It seems inevitable that there should be a similar change in our perception of adult disability. However, more detail is available in a recent publication by the British Psychological Society (4).



1. [Jackson AL, Waters SE. Taking Time – Framework: A trauma-informed framework for supporting people with intellectual disability. NSW Government: Family & Community Services, 2015.](#)
2. [Marcal S, Trifoso S. A Trauma-Informed Toolkit for Providers in the Field of Intellectual & Developmental Disabilities. Center for Disability Services, 2017.](#)
3. [Scotland NEf. Transforming Psychological Trauma: A knowledge and Skills Framework for the Scottish Workforce. 2017.](#)
4. [Skelly A, Anonymous \(Expert by Experience\), Fletcher HK, Flood A, Jones L. Incorporating Attachment Theory Into Practice: Clinical Practice Guideline for Clinical Psychologists working with People who have Intellectual Disabilities. The British Psychological Society, 2017.](#)



### Brexit and Post-Truth: what these mean for Psychiatrists Working in Britain and Ireland.

**Dr John Hillery**



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*Former President of the Medical Council.*

*Dr Hillery has just retired from a post as a Consultant Psychiatrist with Stewart's Hospital Services and the Tallaght Mental Health Services.*

*Based on an address given to the Faculty of Psychiatry of Intellectual Disability Annual Conference in Dublin in October 2017*

I chose the title for this lecture in order to highlight threats to the appropriate practice of scientific professionalism that should concern us as doctors. We must acknowledge them and understand them. They should spur us to focus our energies and skills as professionals and as members of professional groups to the advantage of the patients we aim to serve.



There is a lot written and said about Brexit and Post-truth. For me their import can be distilled in a quote from a speech that was never given. In November of 1963 the then President of the USA John F Kennedy was to give a speech in Dallas. Fate intervened. The quote, if paraphrased, remains relevant to all who think that decisions should be based on evidence: "America's leadership must be guided by the lights of learning and reason or else those who confuse rhetoric with reality and the plausible with the possible will gain the popular ascendancy with their seemingly swift and

simple solutions" (quoted in *An American Melodrama; The Presidential Campaign of 1968* – Chester L., Hodgson G. and Page B.- Penquin Books 1969). I think that today we need to be aware that rhetoric and plausibility are winning the day over the perceived complexity of facts and evidence. This poses a threat to individuals and society in general and professionals and professional groups must respond.

It could be seen as an irony that the President of the College of Psychiatrists of Ireland should be lecturing about the risks of Brexit. The Irish College could be seen to have broken away from the Royal College of Psychiatrists in an operation that could be called perhaps Eriexit. However, the establishment of an Irish College was not a break away but more an evolution on developments of medical training on both sides of the Irish Sea and both sides of the Irish border. Psychiatrists in Ireland had been members of the Royal College of Psychiatrists from its inauguration and there was an Irish Division of the Royal College with members from the 32 counties of Ireland, Northern and Southern. In his seminal history of Irish psychiatry (*Hearing Voices – Irish Academic Press 2016*) Professor Brendan Kelly quotes from a former Chair of the Irish division of the Royal College of Psychiatrists, Professor Tom Lynch, who seemed to speak against an Irish College by pointing out that "psychiatry, rugby and hockey are the only truly joint ventures between north and south". Professor Lynch is further quoted "There was an issue as regards negotiating with the Irish Government when the Chair of the Irish division was from the north but this was solved by the psychiatrists from the south calling themselves the Irish Psychiatric Association during such consultations with the Department of Health in Dublin." Professor Lynch refers to another leading Irish Psychiatrist, Dermot Walsh, as "being keen on having an Irish College of Psychiatry in Ireland" but Lynch's concluded "that requires funding and I don't think its practical". In the end there were three bodies in the Republic of Ireland: the Irish College of Psychiatrists (a division of the Royal College of Psychiatrists); the Irish Psychiatric Association and the Irish Psychiatric Training Committee. The latter was the training body for Irish Psychiatry in the Republic. At that stage training and its inspections were joint activities between the Irish Psychiatric Training Committee and the Royal College of Psychiatrists. Changes in the governance of medical education in the UK led to a need for separation however. In

2009, a single organisation was set up called the College of Psychiatry of Ireland. The name was changed, following a proposal from Dr Des McGrath, to the College of Psychiatrists of Ireland in 2013. The Irish College of Psychiatrists is now the professional body for psychiatrists in the Republic of Ireland. It is recognized by the Irish government through the Medical Council of Ireland as being responsible for the training of psychiatrists and for lifelong learning (Professional Competence) for specialist psychiatrists. There are now over 1000 members of the College and its structure is similar to the Royal College with faculties and sub-committees. The College also has a very active committee made up of service users and carers and psychiatrists called Refocus.

Having dealt with our history I now turn to the issues I opened with. What are the implications of Brexit? To me, these are both practical and philosophical. As regards the practical implications, the more I read and the more I listen the less I think that anyone understands what these are. We hear talks of a “hard-border” between the North of Ireland and the Republic. We hear talk from the North of Ireland and from the UK of the need to continue the special relationship between the Republic of Ireland and the UK and across the border between the counties of Ulster that are in the Republic and the counties that are in the UK. No-one seems sure how this will turn out.

The College of Psychiatrists of Ireland and the Northern Ireland division of the Royal College of Psychiatrists hold joint meetings every three years. At our Winter Meeting in 2016, the keynote speaker was Lord Alderdice. Lord Alderdice is a former consultant psychiatrist and was the first Speaker of the Northern Ireland Assembly. In his address he talked about how the world has changed in his time in politics, nationally and internationally. He was pessimistic in his view of the current situation. He outlined how we have gone from a world with leaders who promoted reconciliation, an attitude that led to such positive outcomes as the peace process in Ireland, to world of leaders whose default position is confrontation. When asked what the Irish College of Psychiatrists and the Northern Ireland Division could do to remedy this, he recommended that we continue to support strong links within the island and with our colleagues in the UK.

“we have gone from a world with leaders who promoted reconciliation ... to world of leaders whose default position is confrontation”

Unfortunately, adding to the confrontational atmosphere is the dismissal of facts and experts. This was seen in the pre-referendum Brexit debates and the U.S. presidential debates and continues to be seen today in the media outings and the social media outings of leaders in all these areas. Coincidentally in 2017 the epidemiologist, Hans Rosling, died. He spent most of his professional life trying to fight falsities with facts. He established an organisation called [Gapminder](#) which is still active today. Rosling is quoted as saying “the world is discussed in terms of feelings and ideologies rather than as an area of knowledge”. As Psychiatrists we are trying to function as experts in an anti-expert environment. Though Michael Gove, the leading Tory politician and Minister for the environment, says that he was misquoted the statement [“this country has had enough of experts”](#) attributed to him seems to me to capture a philosophy that appeals to many people these days. In listening to the media, but also in my daily work, I get the impression that everyone, no matter what their training or lack thereof, is an expert now. I think all of us who work in health services come across people, without our training, who dismiss our opinion if it doesn’t agree with their own. It is the strength and ferocity with which a statement is made, rather than the strength of its position, that counts. George Saunders, the American essayist, discussed this in an essay called ‘The Braindead Megaphone’ (Riverhead Books, 2007 USA). In this essay, he asks us to picture a pleasant social gathering where people are talking in groups and listening to each other. Then a man enters the room with a megaphone and starts to talk through this. What he says does not have any great content but as time goes on people stop talking to each other and gravitate towards him. For George Saunders, the media today is represented by this image with all attention eventually going to the person who speaks loudest rather than those who speak from knowledge. Harry Frankfurt, the American philosopher, has an excellent book called ‘On Bullshit’ (Princeton University Press 2005). Professor Frankfurt outlines a world that encourages bullshit. He refers to media panels where everyone is meant to comment on everything that is discussed, even if it is well outside their area of expertise. We see this every day when politicians are asked to talk about things that they obviously know nothing about but feel that they have to comment on once they are asked.

Frankfurt differentiates between bullshit and lies. He says that to lie requires knowledge because you need to know what the truth is before you can tell a lie, whereas bullshit needs no knowledge at all. Lies may seem to be more malevolent but both lies and bullshit can have an equally deleterious effect on social cohesion and discourse. In medicine, we see examples in the recent debates in Ireland about the safety of the HPV vaccine where both a Government Minister and a Catholic

Bishop became involved in the campaign that claimed that the vaccine poses a risk to health, though neither had any facts to back this up. I would like to think that they were involved in bullshit rather than lies. The controversies about the links between the MMR vaccine and autism have led to a fall off in childhood vaccination with subsequent increased risks to individuals and society. The 'scientific' basis for the positions held by some have been discredited. The motivations would seem to be questionable in a way that suggests that this was more than simple bullshit. This has led to one of the medical leaders in the campaign being [struck off the Medical register by the General Medical Council](#) though the [principal protagonist seems unbowed](#). Dr Wakefield's persistence and the support he has in high places leads me to the subject of Post-Truth.

What is Post-Truth? The Oxford Dictionaries declared 'Post-truth' the [word of the year for 2016](#). Post-truth is not a new concept and can be traced back to the 1990's. Oxford Dictionaries claim that its use peaked in 2016 with an increase in the latter half of 2016 of its use of 2000%. The Oxford Dictionaries defines it as an 'adjective relating to or denoting circumstances in which objective facts are less influential in shaping opin-



ion than appeals to emotion and personal belief'. Examples are multiple in the last few years but include many of the claims of the President of the United States and his staff and the promises during the Brexit campaign (see for example: <https://www.theguardian.com/books/2017/may/12/post-truth-worst-of-best-donald-trump-sean-spicer-kellyanne-conway> or

<https://www.newstatesman.com/politics/uk/2017/09/boris-johnson-resurrects-leave-campaign-s-350m-nhs-fantasy>).

But what does this mean for professions? The characteristics of a professional are as follows (Gardner, H. & Shulman, L. S.; Daedelus Summer 2005; American Academy of Arts and Sciences):

1. A commitment to serve in the interests of clients in particular and the welfare of society in general;
2. Have a theoretical knowledge base;
3. Have a mastery of a domain of practice;

4. Deal with uncertainty, common novelty and unpredictability;
5. Learn from experience;
6. Connect learning to practice.

Among the key words here are knowledge base; mastery of a domain of practice; and connecting learning to practice. The post truth world is incompatible with such practices but such practices are necessary for a functioning society. The role of the Colleges then is key. The [objective of the College of Psychiatrists of Ireland](#) is to promote excellence in the practice of psychiatry. However, people have been critical of collegiality in the past. George Bernard Shaw and his statement that "All professions are conspiracies against the laity" comes to mind immediately (The Doctor's Dilemma; first published 1911). In Ireland the Lourdes Hospital Enquiry pointed to collegiality as one of the reasons why an obstetrician was allowed to carry out [unnecessary hysterectomies](#) without anyone questioning the practice. Despite many examples that can be quoted of circumstances where patients have felt let down by their doctors the available research indicates that the public trusts doctors. The Irish Medical Council did a [survey of trust in professions in Ireland in 2015](#) which showed that 91% of people trust doctors whereas only 18% trust Members of our Parliament. The [Mumsnet Report of 2016](#) showed that 91% of people believe that doctors tell the truth whereas only 15% believe politicians do. As doctors, we do have a platform of trust which gives us responsibilities also. There is strength also in collegiality and a responsibility to use this collegiality to disseminate fact-based information.

*"91% of people believe that doctors tell the truth whereas only 15% believe politicians do"*

I believe that the evidence shows that the medical profession is still in a position of leadership in society. To continue to hold this position, we must be manifestly experts who are evidence based. We must interact with society. We must use disagreements with others in a formative way to exhibit facts and come to conclusions based on facts and evidence based information. We must be open and explicit about uncertainty rather than claiming outcomes that are not true or not backed by fact. We must be heard, and I believe that the Colleges are the platform for this. There are problems however in the modern megaphone era in that professions are not necessarily good at agreeing with each other; or not necessarily good at explaining our positions as we tend to feel we have to exhibit

all the facts on an issue when we are talking about it rather than competing in a noisy forum which requires pithy sound bites.

We need to be experts at professing evidence based positions in a way the media and the public can digest and absorb them. Post-truth and bullshit damage society, damage social discourse and can physically damage people if they follow the positions of those who use emotional rhetoric and plausibility rather than those who use facts. However to counter them we must be equally vociferous in promoting our positions on issues that are important to us as medical professionals.

Finally, what I have said heretofore is by way of supporting a need for us to work together across whatever real or philosophical borders are imposed. We need to continue working together as professionals and professional bodies with joint interests in using evidence in the public interest despite the practical and the philosophical atmospheres that we work in. These are being created by rhetorical political outlooks such as Brexit and Post-Truth. We need to be sure about our facts and evidence and also to be open about our doubts when they exist. We need to support our Colleges and work together in a collegiate way so as to remain leaders in society. It is in our collegial work that we can be strongest as advocates for our patients and for an evidence based society.

I finish with a quote from the American diplomat and politician Senator Daniel P Moynihan: "Everyone is entitled to their own opinions, not their own facts".



## News from Europe

**Dr Ken Courtenay**

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**European Psychiatric Association (EPA) @EPA\_MHID**



The EPA is a European body for all psychiatrists practising in Europe. Thirty-four national psychiatric associations are members of the Association of which the Royal College is one of the major bodies affiliated to it.

The EPA Section of Mental Health in Intellectual Disabilities (MHID) was created in 2014 with the aim of raising awareness on MHID among psychiatrists in Europe. The specialty in Europe is recognised in the UK and Ireland only but it is often general psychiatrists and child psychiatrists in other healthcare systems who care for people with ID.

The activities of the Section are varied. At the EPA Congress 2017 in Florence, the Section collaborated with the Ethics Committee in a joint symposium on the role of ethics in MHID. The speakers came from Denmark, Ireland, and UK. In 2018 the Section MHID had its most successful Congress in Nice where it held a workshop on Autism attended by 140 delegates. Speakers were from Ireland, Poland, UK, Germany and Italy. Members of the Section regularly submit ePoster presentations to the Congress.

The Section MHID drafted its guidance paper on mental health in ID that is expected to be accepted in 2018. The purpose of the guidance is to be a resource for general psychiatrists across Europe working with people with ID that will be published in the European Psychiatry journal. The Section MHID plans to convene a two-day educational event in 2018.

Membership of the EPA is €100 annually providing access to European Psychiatry journal, reduced registration fees at EPA conferences, and access to colleagues across Europe

through the EPA website ([www.europsy.net](http://www.europsy.net)). To become a member of the Section MHID, contact Bhathika Perera ([bhathika.perera@nhs.net](mailto:bhathika.perera@nhs.net)), Secretary EPA Section MHID.

**European Association Mental Health in Intellectual Disability (EAMHID) @EAMHID**



EAMHID was established in 1992 through a collaboration between professionals in MHID in the Netherlands and the UK. It is a specialist association of researchers and practitioners from various clinical backgrounds across Europe. It differs from the EPA by its specialist nature with members from a variety of professional backgrounds.

The Association convenes a two-yearly Congress over three days that attracts over 500 delegates to exchange research findings and practice innovations. The next Congress will take place in Barcelona **23 - 25 May 2019**.

A new innovation in 2018 by EAMHID led by the President, Roger Banks, is to combine the Executive Committee meetings with masterclasses on MHID in centres across Europe in order to engage more with local practitioners. Masterclasses are planned to take place in Zagreb in Croatia and Turku in Finland in 2018.

Membership of EAMHID ([www.mhid.org](http://www.mhid.org)) provides discounted rates to the Congress, on-line access to the journals JIDR, and its regular Newsletter. EAMHID will provide a bursary for participants from Low and Middle Income countries to attend the Congress.

To join EAMHID, contact Herman Wouters ([herman.wouters@stichtingdelacroix.be](mailto:herman.wouters@stichtingdelacroix.be)). The annual membership fee is €85. Updates on EAMHID are available on Twitter @EAMHID.

### The Legislative Framework Governing the Care and Treatment of Children and Young People in England and Wales

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Having knowledge of the legislative framework governing the care and treatment of children and young people is essential for clinicians working with those under the age of eighteen years. The legal framework is complex and how legislation is implemented is governed by ever-changing case law. This area is further complicated by over sixteen year olds being considered under a different legislative framework than those below sixteen years.

Key guidelines and pieces of legislation include The United Nations Convention on the Needs of the Child (UNCNC), The Human Rights Act, The Children Act, The Mental Health Act and the Mental Capacity Act.

The UNCNC does not recommend a specific age when children should be viewed as having capacity to make decisions regarding their care and treatment. However, it advises that 'States Parties shall assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child.'

The Council of Europe's European Convention on Human Rights and Biomedicine Article 6 leaves each country to define when a minor is viewed as competent to give a valid consent, but insists that, for those viewed in law as not capable of providing consent, the treatment must directly benefit the minor, the authorisation of a legal representative is obtained and 'the opinion of the minor shall be taken into consideration as an increasingly determining factor in

proportion to his or her age and degree of maturity'.

In England and Wales, the age when young people are judged to have capacity to consent to decisions relating to their care and treatment is sixteen years. Prior to this, young people may be judged to be competent to make decisions regarding their treatment and are often referred to be Gillick or Fraser Competent. Both Gillick competency and Fraser guidelines refer to the legal case *Gillick v West Norfolk & Wisbech Area Health Authority* [1985] UKHL 7 (17 October 1985). This case was concerned specifically with looking at whether or not doctors could provide under sixteen year olds with contraceptive advice or treatment without the consent of the parent. The original case was heard in 1982 and concerned Mrs Victoria Gillick asking the Court to try to stop doctors giving such advice without the parent's consent. The case went to the High Court and Mrs Gillick's claims were dismissed by Mr Justice Woolf. This decision was reversed by the Court of Appeal and finally went to the House of Lords in 1985 where the Law Lords - Lord Scarman, Lord Fraser and Lord Bridge - ruled in favour of Mr Justice Woolf's original decision that a child under the age of sixteen could, in certain circumstances, give consent to medical treatment, including receiving contraceptive advice and contraceptive aids or have an abortion without the knowledge or agreement of the parent. Lord Scarman commented that '...it is not enough that she should understand the nature of the advice which is being given, she must also have a sufficient maturity to understand what is involved'. These comments are referred to as the test of "Gillick competency".

Subsequently, these guidelines have been used to help ascertain the maturity of a child, whether they are able to make decisions for themselves and that they understand the significance of the decisions they make. A child under the age of sixteen years is said to be a 'Gillick competent' child if they are able to show a level of maturity and understanding that enables them to be able to assess the nature, risks and the outcome of any proposed course of action. 'Gillick competence' has a broader meaning than 'Fraser competence' and describes children who are able to give their consent to matters other than medical matters with-

out the consent of their parents.

The 'Fraser guidelines' specifically relate only to contraception and sexual health and the House of Lords concluded that advice can be given in this situation as long as:

1. He/she has sufficient maturity and intelligence to understand the nature and implications of the proposed treatment;
2. He/she cannot be persuaded to tell her parents or to allow the doctor to tell them;
3. He/she is very likely to begin or continue having sexual intercourse with or without contraceptive treatment;
4. His/her physical or mental health is likely to suffer unless he/she received the advice or treatment;
5. The advice or treatment is in the young person's best interests.

The case of Gillick left open a number of issues, including the extent to which parents have rights to consent on their child's behalf, to have information about their child's treatment and whether not Gillick applies to refusals of treatment.

For children below the age of sixteen years who lack competence to make decisions those with parental responsibility can provide consent. Parental responsibility is a concept defined by the Children Act 1989 and is defined as:

- All birth mothers;
- Fathers married to the mother at the time the child was born;
- Fathers who are not married to the mother, but are registered on the child's birth certificate - the registration or re-registration must have taken place after December 2003;
- Civil partners and partners of mothers registered as the child's legal parent on the birth certificate;
- Any person granted parental responsibility by the Court.

However, those with parental responsibility can only consent to decisions within the scope of parental responsibility. Although this is a term defined within the 2015 Code of Practice to the Mental Health Act, the Code its application is not limited to treatment for mental disorder, but rather it is applied more generally to all treatments. There are a number of factors that determine whether a decision would fall within the scope of parental responsibility, including if the decision in question would be one that a parent should reasonably be expected to make. Considerations when making decision on this issue include:

1. What is considered normal practice in our society?
2. The type and invasiveness of the proposed intervention;
3. The age, maturity and understanding of the particular child/young person;
4. The extent to which the child/young person agrees/resists;
5. Relevant human rights' decisions of the Court.

In addition, it is important to consider whether there are any factors that might undermine the validity of this particular person's parental consent, which would include:

1. If a parent cannot make the decision - for example, incapacitated;
2. If a parent is unable to focus on the best interests of the child/young person;
3. If there is significant distress of parent - i.e. to the extent that they are overwhelmed;
4. If there is disagreement between parents.

If the decision is one which a parent would not reasonably be expected to make, or if relying on that parental consent would not be appropriate, the decision can be referred to the Court to.

Unless the treatment in question is irreversible or is an immunisation, the consent of one person with parental responsibility is usually sufficient. It will not be appropriate, however, to rely on parental consent if another person with parental responsibility strongly disagrees with the decision and is likely to take action to prevent intervention. If consensus cannot be reached, the decision should be referred to the Court.

For sixteen and seventeen year olds, the principal piece of legislation governing decisions regarding their care and treatment is the Mental Capacity Act (MCA) 2005. However, it should be noted that not all of the provisions in the Act apply to this age group.

The MCA 2005 starts with the premise that all individuals over the age of sixteen years have the capacity to make decisions for themselves, unless they can be shown to lack capacity. The Act sets out a single clear test for assessing whether a person lacks capacity to make a particular decision at a particular time. The Code of Practice outlines a two-stage test of capacity:

1. Does the person have an impairment of the mind or brain? (Diagnostic Test);

2. If so, does that impairment or disturbance mean that the person is unable to make the decision in question at the time it needs to be made? (Functional Test).

The impairment or disturbance in the functioning of the mind does not need to be one of the diagnoses in the ICD-10 or DSM-V. It can include conditions which produce a temporary impairment, including medical conditions causing confusion, drowsiness, concussion and the symptoms of drug or alcohol abuse.

The elements of the functional test are found in s.3 (1) MCA 2005, which states that P is unable to make a decision for himself if he is unable to:

- understand the information relevant to the decision; or
- retain that information; or
- use or weigh that information as part of the process of making the decision; or
- communicate his decision (whether by talking, using sign language or any other means).

In circumstances when a young person lacks capacity, as defined by the MCA 2005, practitioners will be able to make decisions in relation to a young person's care and treatment, if such decisions are in the young person's best interests and otherwise carried out in accordance with the principles and provisions of the Act. Treatment can also proceed with the consent of someone with parental responsibility, as long as the treatment falls within the scope of parental responsibility.

There may be reasons why a young person is unable to make decisions which do not fall within the scope of the MCA 2005. Guidance in the Act's Code of Practice states that there may be cases when young people are unable to make a decision, but this may not be because they are judged to have an 'impairment of, or disturbance in, the functioning of the mind or brain'.

The guidance highlights that a young person may not be able to make a decision by reason of their lack of maturity - this group will fall out of the scope of the MCA 2005. This means that sixteen and seventeen year olds are distinct from adults under the Act, in so far as consent can be provided on their behalf by someone with parental responsibility, where the young person is incapable.

The issue regarding the refusal of both competent and capacitous young people to refuse treatment is less straight forward.

General Medical Council guidelines on the care and treatment of nought to eighteen year olds state 'Respect for young people's views is important in making decisions about their care. If they refuse treatment, particularly treatment that could save their life or prevent serious deterioration in their health, this presents a challenge that you need to consider carefully. Parents cannot over-ride the competent consent of a young person to treatment that you consider is in their best interests, but you can rely on parental consent when a child lacks the capacity to consent. In England, Wales and Northern Ireland, the law on parents over-riding young people's competent refusal is complex. You should seek legal advice if you think treatment is in the best interests of a competent young person who refuses.'

The Court can over-ride the decision of a competent/capacitous young person to refuse treatment, but they would need to be satisfied that it is in the young person's/child's best interests. The wishes of a capacitated young person or competent child are important; however, they are not absolute and may be out-weighed by other factors, such as a right to life under Article 2 ECHR. The Courts are expected to undertake a balancing exercise between the wishes and feelings of the competent child and any harm that the child is at risk of suffering by refusing the treatment.

It is extremely important that clinicians working with under eighteen year olds, particularly when considering hospital admission, have an understanding of the issues relating to deprivation of liberty. Article 5 of the Human Rights Act states 'Everyone has the right to liberty and security of person. No one shall be deprived of his liberty save in the following cases and in accordance with a procedure prescribed by law'. This includes the lawful detention of persons of 'unsound mind' and applies to everyone irrespective of age. A key consideration for practitioners is whether or not any proposed treatment or care arrangements will amount to a deprivation of the child or young person's liberty. If it does, consideration will need to be given to the legal framework authorising such an arrangement. It had long been established that parents cannot consent to their children's deprivation of liberty and, in addition, the Deprivation of Liberty Safeguards do not apply to under eighteen year olds.

The definition of what is a deprivation of liberty was clarified in the *Cheshire West and Chester Council v P* [2014] ruling. In

reaching this decision, the Supreme Court identified that to determine whether a person (without the mental capacity to consent to the arrangements) is being deprived of their liberty, the following 'acid test' should be applied:

- Is the person subject to continuous supervision and control?
- Is the person free to leave? (The focus is not on the person's ability to express a desire to leave, but on what those with control over their care arrangements would do if they sought to leave).

In all cases, the following are not relevant to the application of the test:

1. The person's compliance or lack of objection;
2. The relative normality of the placement (whatever the comparison made);
3. The reason or purpose behind a particular placement.

The restriction and care regime that is ordinarily in place in inpatient psychiatric units would therefore be viewed as fulfilling the 'acid test'. As the majority of young people with intellectual disability will lack competence/capacity to consent to such arrangements, it had been the case that this group of young people were being admitted under the Mental Health Act, no matter what their age or wishes of their parents. However, there has been a recent case that has considered this issue. In *Trust A v X and Others* [2015] EWHC 922 (Fam), the child at the centre of the proceedings was aged fifteen years with a number of difficulties, including Attention Deficit Hyperactivity Disorder, Asperger syndrome and Tourette syndrome. He was informally admitted to hospital ('hospital B') in 2013 for a multi-disciplinary assessment and treatment. The psychiatric unit had six beds, with a school room attached to the building; it was locked; he could not leave with staff or a family member; he was under thirty-minute observation, but sought out more regular contact with staff. He left the unit daily, accompanied by staff, going off site for activities, including in the community on a one-to-one basis. D was assessed as not being Gillick competent to consent to his residence and care arrangements. In light of the decision in *Cheshire West*, the hospital Trust issued an application in December 2014 under the inherent jurisdiction of the High Court seeking a declaration that the deprivation of D's liberty by the Trust was lawful and in his best interests. In his judgement, Mr Justice Keehan made it very clear that he was confining his decision to that of D aged fifteen years and the hospital in question. He did not give any wider guidance on the approach to a child of sixteen years or over under the MCA 2005, nor did he comment on any future unidentified residential unit outside of the hospital. He considered the law on

parental consent and, in the process, distinguished and clarified the obiter observations of Lord Justice Thorpe in *RK v BCC and others* [2011] EWCA Civ 1305, in which it was said that a parent may not lawfully detain or authorise the deprivation of liberty of a child. All parties had accepted, by closing submissions, that the circumstances in which D was accommodated amounted to a deprivation of liberty. However, the judge did not agree with the Local Authority's submission that *Cheshire West* did not apply to young people aged under the age of sixteen years, stating 'what it means to be deprived of liberty is the same for everyone, whether or not they have a physical or mental disability'. The hospital Trust argued that D's parents could not give consent to the deprivation of his liberty and the judge was clear that this issue was case specific and he took into account D's disabilities and age as important factors. Although ordinarily he viewed the decision to keep a fifteen year old child under constant supervision and control as an inappropriate exercise of parental responsibility, he found that in D's case, given his disabilities, the fact that the parents were following medical advice and the parents' active involvement in D's care at hospital, he considered it to be entirely proper. He therefore ruled that it is possible for parents to agree, as a proper exercise of their parental responsibility, that a child can be placed in a setting which would otherwise amount to a deprivation of the child's liberty.

Subsequent rulings have further clarified this area. In the case of *AB (A Child: Deprivation of Liberty)* [2015] EWHC 3125 (Fam), an application was made to the Court by the Local Authority to authorise the deprivation of liberty of a child in its care, who had been placed in a residential children's home.

This case concerned AB, a fourteen year old boy with a moderate severe learning disability and Attention Deficit Hyperactivity Disorder, who had been placed at a residential children's home under an Interim Care Order. AB was subject to continuous supervision and control and it was agreed among all of the parties that he was being deprived of his liberty (as opposed to his liberty merely being restricted). The Court was asked to determine whether it could authorise the deprivation of AB's liberty and, if so, under what statutory provision. Mr Justice Keehan was clear that, as an instrument of the State, the Local Authority could not consent to the deprivation of liberty of a child in its care; to do so would be in breach of Article 5 of the ECHR. Therefore, it was concluded that there were two possible ways in which to authorise the deprivation of AB's liberty: first, pursuant to s.25 of the Children Act 1989; or second, under the inherent jurisdiction of the Court. The judgment also makes clear that Local Authorities are under a duty to consider whether any children in need or looked after are subject to restrictions amounting to deprivation of liberty. This obviously has a significant impact on Local



Authorities who place Looked After young people in residential settings in which the level of supervision would amount to a deprivation of liberty.

**Summary**

Consent for children and young persons is not a simple issue and professionals should ensure that any assessments of capacity/competence are rigorous and comprehensively recorded. Case law is ever-changing and keeping up-to-date with

## Summary

Consent for children and young persons is not a simple issue and professionals should ensure that any assessments of capacity/competence are rigorous and comprehensively recorded. Case law is ever-changing and keeping up-to-date with developments in this field is essential in ensuring that clinicians' practice is in-keeping with the appropriate legal framework.



## Prescribing of Psychotropic medication for people with an intellectual disability (ID) in the community: audit cycle of interventions to improve clinical practice

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Deanery



be undertaken on a regular basis.

### Methods

We conducted a retrospective audit in 70 individuals across 7 community teams. A random sample of patients was generated and data was extracted using a standardised data collection tool. Interventions were made to improve clinical practice and 6 months later a re-audit was carried out using a similar procedure.

### Recommendations

The results of this initial audit highlighted either a gap in clinical practice or poor documentation. As a consequence of this initial audit a change in practice was brought about via 2 key recommendations:

- I designed a checklist adapted from self-assessment framework in the faculty report that clinicians could use to rationalise their prescribing practice and where appropriate, taper and stop psychotropic drugs.
- Implementation of objective evaluation of treatment response and side effects using a standardised instrument; the Clinical Global Impression (CGI) scale. This is freely available online, can be administered in a matter of minutes by a clinician who knows the patient well, and generates a summary score of improvement as well as the efficacy index.
- Using both narrative accounts and standardised measures in this way can help the prescriber determine objectively which drugs are ineffective and aid the process of stopping them in consultation with patients and their carers. Both of these forms were sent to all relevant doctors and administrative staff and made available in all clinic rooms.

### Background

In 2017 the Faculty conducted a survey of 95 members to ascertain their level of awareness of [STOMP](#) and the Faculty's commitments under the [pledge](#). Areas for improvement included structured reviews and monitoring of medication using an outcome scale and assessing for the presence of side effects. This audit cycle of interventions describes how objective measures of the effectiveness of prescribing have been incorporated into practice in Black Country partnership NHS foundation trust.

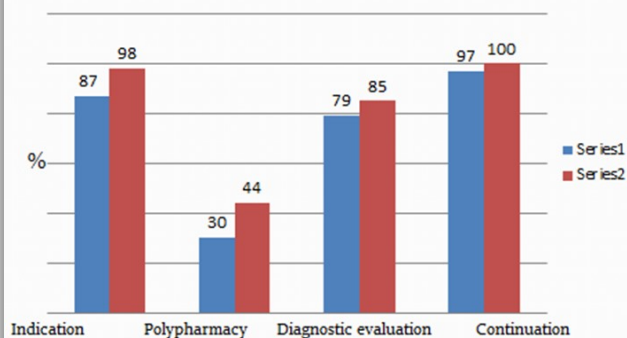
### Aims

To evaluate the current psychotropic prescribing practice across community ID teams against the standards set in Psychotropic drug prescribing for people with intellectual disability, mental health problems and/or behaviours that challenge: practice guidelines ([FR09](#)) and to improve areas where the standards are not achieved.

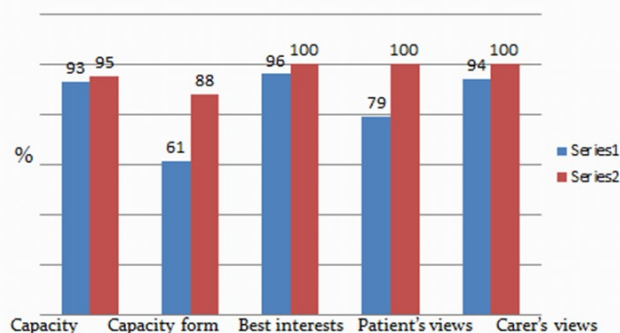
### Standards

1. The indication(s) and rationale for prescribing the psychotropic drug should be clearly stated including whether the prescription is off-label, polypharmacy or high dose. It should include diagnosis as well narrative account of target symptoms.
2. Consent-to-treatment procedures should be followed and documented.
3. There should be regular monitoring of treatment response and side-effects including objective evaluation using standardised measures.
4. Review and evaluation of the need for continuation or discontinuation of the psychotropic drug should

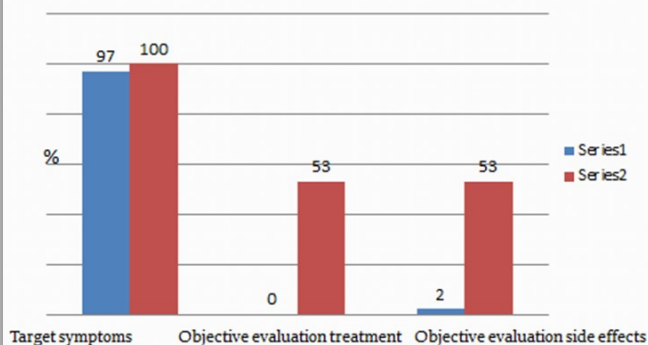
## Standards 1 + 4



## Standard 2



## Standard 3



### Results

- More clinicians had recorded the indication for prescribing including the rationale for polypharmacy.
- There was an increase in the recording of a full diagnostic evaluation.
- In the second cycle 100% clinicians had reviewed the need for continuation or discontinuation of the psychotropic drug.

- There was an increase in the recording of capacity to consent to medication including an increase in the use of a specific capacity form from (61-88%)
- In the second cycle there was 100% compliance of best interests procedures being carried out and patient's and carer's views being recorded
- There was an increase in the recording of target symptoms to 100% compliance
- The biggest difference was in the improvement in the use of objective evaluation of treatment response from (0-53%) and side effects from (2-53%) with the use of the [Clinical Global Impression Scale](#). This hopefully has shifted the culture of resistance to using structured outcome measures in our clinical practice.

### Conclusion

The results showed an improvement in all 4 standards set for this audit following the interventions. Areas of Good practice included documentation of indication for prescribing, capacity assessment and evaluation of continuation of psychotropic medication. Areas for further improvement include recording the rationale for polypharmacy and off label medication. There is also scope for further improvement of the use of objective evaluation of treatment response and side effects using the Clinical Global Impression Scale. We have since further modified this form to include items which will make it easier to use and keep in the patient record including date and signature of the clinician completing the rating. A reminder about the checklist and CGI form has been sent to all relevant staff within the trust, and has been reinforced during a teaching session. A further recommendation is to include the use of carer's information as one of the obstacles to an effective discussion during clinic appointments is often the poor quality of information provided by paid and family carers. The voluntary organisations disability group has produced a useful leaflet '[preparing to visit a doctor](#)'. This can be given to carers and care organisations so that they can become well prepared for the clinic session. Finally we plan to re-audit to complete the 3 year cycle and ensure recommendations are embedded as business as usual to ensure the optimisation of psychotropic medication prescribing in our clinical practice.

## Intellectual Disability, Capacity to Consent to Sex, and the Law

**Dr Shakeel Islam &**

**Dr Sanjay Nelson**

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The assessment of capacity for sex is a challenge to psychiatrists. We present a guide to assessment of capacity, giving a background to relevant law, links to case law and tools for assessment. Why not test your knowledge with some of these T/F questions before reading on:

1. It is an offence for staff in hospitals and residential homes to have a sexual relationship with a patient
2. Morality is a criteria of capacity to enter into sexual relations
3. Capacity assessment to enter into sexual relations is a functional test
4. Sexual Offences Acts 2003 uses a diagnostic criterion for capacity to consent to sex
5. In civil law capacity to consent to sex is person specific

[Answers at the end...](#)!

### **Relevant legislation**

The Mental Health Act of 1983 made it an offence for staff members in hospitals and residential homes to have a sexual relationship with patients.

The Sexual Offences Act 2003 currently in place is capacity based rather than the diagnosis based approach of Sexual Offences Act of 1967. It is an offence if the person is unable to refuse due to: a) lacking capacity, e.g. if they did not have sufficient understanding of the nature of the act, the reasonably foreseeable consequences, or for any other reason, and b) being unable to communicate a choice. The Act specified offences for particular roles, e.g. carers and teachers, and introduced longer sentences, of up to life imprisonment.<sup>1</sup>

In 1999, the Courts saw the case of R v. Jenkins, a woman with Severe ID made pregnant by a support worker. The expert witness for the prosecution showed that she did not have capacity to consent to sex, nor did she have understanding of

her pregnancy. An argument was put forward by the judge it 'was not necessary to understand the implications of sexual intercourse, only to have an understanding of the act itself and that there was therefore no case to answer'. The alleged perpetrator thus walked free. This case highlighted the extreme vulnerability of adults with ID despite legislation in place.<sup>2</sup>

### **Web links to case law:**

The following links to case laws identify the differing opinions amongst judges, the varying tests put forward in the test of capacity, and the different outcomes that can be reached.

[1\) LA \(Local Authority\) v MM, 2007, Justice Munby.](#) In this case, capacity to consent to sex was deemed to be issue specific and not person specific, i.e. that a person needs to have capacity to consent to sex in general, and not related to capacity to consent to sex with a particular proposed partner.<sup>3</sup>

[2\) R v C, 2009, Baroness Hale.](#) In this case it was opined that it was difficult to think of an activity which was more person- and situation-specific than sexual relations. Concluded that one does not consent to sex in general, one consents to this act of sex with this person at this time and in this place.<sup>4</sup>

[3\) DBC v AB, 2011, Justice Mostyn.](#) Here the Judge did not agree with capacity to consent being person specific, and considered the practicalities of person-specificity, i.e. is the LA supposed to vet every proposed sexual partner? Expert opinion regarding the test of capacity, which included understanding of age and consensual consent, was rejected as this would elevate the capacity test.<sup>5</sup>

[4\) LA v H, 2012, Justice Hedley.](#) In this case the issue of morality was considered but it was opined that morality could not be considered as part of the capacity test, as there is no workable test.<sup>6</sup>

[5\) IM v LM, 2014, Sir Brian Leveson.](#) Here, The Court of Appeal approved the guidance given by judges of the Court of Protection, that the test for capacity to consent to sex should not be overly demanding and should not be "divorced from the actual decision-making process carried out in that regard on a daily basis by persons of full capacity", which "is largely visceral rather than cerebral, owing more to instinct and emotion than to analysis".<sup>7</sup>

## **Assessment of capacity to consent to sex and management considerations**

When assessing, the assessor needs to know the person's understanding of:

- a) The mechanics of the act
- b) The health risks involved, the acquisition of sexually transmitted and sexually transmissible infections
- c) Sex between a man and a woman may result in pregnancy
- d) Choice, and that she/he can refuse

Good practice in further assessment should also take into consideration:

- Details regarding current behaviour patterns
- Details on relevant risk issues
- Details on whether the person with ID has received sex education and information on whether they benefited from this
- Considering the legality of what they are doing
- Understanding that either person has the right to say no at any time
- Understanding that violence and coercion have no place in a consenting relationship.

The British Institute of Learning Disabilities (BILD) has developed a capacity assessment tool titled 'Exploring Sexual and Social Understanding', which is divided into 2 parts. Part A looks at the main issues that the person needs to understand and communicate to be able to have capacity to have sex. Its sections include: identifying the private parts of the body; identifying sexual behaviour and identifying the consequences of sex. Part B is completed if the person has capacity or may have capacity with further education. Its sections include: Identifying where it is and is not appropriate to have sex; issues relating to 'saying no'; identifying power issues; identifying issues around age and illegal relationships; other risk issues. The potential outcomes are 1) Can consent to sex; 2) Can't consent, but education may be beneficial; 3) Need to re-assess once the education has been completed; 4) Can't consent, giving the reasons why this judgement has been made.<sup>8</sup>

Sex and the 3 Rs: Rights, Risks and Responsibilities, is a sex education resource for staff that provides a framework to undertake sex education work which acknowledges the realities of sexual relationships for many people with ID. The pack contains drawn images which cover an extensive range of issues relating to sexuality, with suggestions for assessment and directly tackles difficult subjects, including pornography, sexual abuse of children, consent in relationships and safer sex.<sup>9</sup>

Studies including Lindsay et al. 1992, Caspar & Glidden 2001

have shown that people do gain knowledge following sex education, though it is not always clear whether people are then able to apply this theoretical knowledge to the real world.<sup>10, 11</sup>

## **Conclusion**

Assessment of capacity to consent to sex can be a challenge, and there is no hard and fast acid test as evidenced through the case law to date. Nonetheless the assessment itself should be a functional test as defined by The Sexual Offences Act 2003, the parts of which feature consistently are detailed above.

In the Courts, there has been discrepancy as to whether capacity to consent to sex is issue specific or person specific, on one hand to protect vulnerable adults from abuse and exploitation, and on the other hand to protect their human rights and promote normalisation. As it stands, the capacity to consent to future sexual relations can only be assessed on a general and non-specific basis, ie consent to sex in general and not on case by case basis. Although morality plays an important component in sexual relations, there is no workable test and therefore has not specifically been considered in assessment of capacity.

Several dilemmas remain: What to do about vulnerable women and men who have capacity in legal terms but make unwise decisions? Should questions of morality and emotional consequence be considered? Is capacity to consent to sex just issue specific and not person specific? Judgments thus far are between themselves not capable of reconciliation. Have the Courts been asked to answer an impossible question when it comes to ruling on capacity to consent?

Local authorities will need to consider what arrangements can be put in place to support decision making by adults who do have capacity to make decisions about sex, but who would nonetheless be vulnerable to exploitation and abuse.

To finish, here's those answers on the True or False!

1) T, 2) F, 3) T, 4) F, 5) F

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4) [http://www.mentalhealthlaw.co.uk/Text:ICLR\\_R\\_v\\_C\\_\(2009\)\\_UKHL\\_42](http://www.mentalhealthlaw.co.uk/Text:ICLR_R_v_C_(2009)_UKHL_42)

5) [http://www.39essex.com/cop\\_cases/a-local-authority-v-h/](http://www.39essex.com/cop_cases/a-local-authority-v-h/)

6) <http://www.familylawweek.co.uk/site.aspx?i=ed96128>

7) [http://www.39essex.com/cop\\_cases/im-v-lm-and-others/](http://www.39essex.com/cop_cases/im-v-lm-and-others/)

8) <http://www.bild.org.uk/our-services/books/essu/>

9) <https://www.pavpub.com/sex-and-the-3-rs/>

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## The Intensive Interaction approach: communication learning, social inclusion, emotional well-being, human rights

**Dr Dave Hewett and  
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Intensive Interaction is a gently socially dynamic approach to developing the very earliest communication abilities for people with ASD and/or severe and profound learning difficulties. The target group comprises people of all ages who clearly present as being at the earliest levels of development, usually pre-verbal, frequently socially isolated. However, it is increasingly recognised that people who have autism, for instance, who may use words and phrases richly, can nonetheless still benefit hugely from Intensive Interaction routines and its focus on all the communication development that comes before the onset of speech and comprises the basis of social communication.

In the Intensive Interaction literature, these attainment areas are characterised as the 'Fundamentals of Communication' (Nind & Hewett 1994, 2005, Hewett, 2012), (Fig. 1). Further outcomes are also increasingly recognised within the fundamental psychological and emotional developments that beneficially go hand in hand with communication advancement in usual development and which are clearly major aspects of the progress of the beneficiaries of Intensive Interaction input (Hewett 2018 in press).

### The Fundamentals of Communication (FOCs)

- |  |  |
|--|--|
| <ul style="list-style-type: none"> <li>• enjoying being with another person</li> <li>• developing the ability to attend to that person</li> <li>• concentration and attention span</li> <li>• learning to do sequences of activity with a person</li> <li>• taking turns in exchanges of behaviour</li> <li>• sharing personal space</li> <li>• learning to regulate and control arousal levels</li> </ul> | <ul style="list-style-type: none"> <li>• using and understanding eye contacts</li> <li>• using and understanding facial expressions</li> <li>• using and understanding other non-verbal communications</li> <li>• using and understanding physical contacts</li> <li>• vocalising and using vocalisations meaningfully (including speech)</li> </ul> |
|--|--|

4

(from: Nind & Hewett 1994, 2005)

Intensive Interaction was developed during the nineteen-eighties by a special school staff team, initially as a teaching/learning approach (see Hewett 2012), though as its use has widened in services for children, adults (and increasingly with older adults suffering the cognitive decline of late stage dementia), the social inclusion and human rights aspects of having available such a communication environment have been emphasised and advocated (see Firth 2009). Indeed, the Intensive Interaction literature is increasingly promoting the realisation that human communication is about so much more than the vocabulary for basic needs and wants. Whilst being a developmental programme of continuing progress with communication, Intensive Interaction is also simply a means of creating and enjoying the general 'chit-chat' of purely social communication at all levels of ability. Relaxed, apparently purposeless chit-chat is actually the main, psychologically and emotionally fulfilling, function of communication for all of us (Hewett, 2012b).

The techniques and practices of Intensive Interaction were developed by highly practical trial and error, but also by drawing on the rich research literature on parent- infant interaction models (Schaffer 1977). These studies show infants learning the intricacies of communication within warm, enjoyable, dynamically responsive, free-flowing interactions with the available adults.

Correspondingly, Intensive Interaction promotes active learners - dynamic participants within simple, familiar but increasingly sophisticated interaction activities. The key is the member of staff deploying simple principles of action and being comfortable with creatively using themselves – face, voice, body language, sense of presence, as the major resource for the other person. The absolute key principle is the ability to slow down, do less, leave time and space for the person's activity, and broadly, to let them lead (see Fig. 2).

Over the past 20 years Intensive Interaction has become increasingly well researched across a range of care and educational settings (Firth 2017) and is taught in many degree or post graduate courses (Speech & Language Therapy, Learning Disability Nursing, Clinical Psychology, Disability Studies), and included in a number of UK government and NGO health and special education guidelines.

Intensive Interaction is specifically identified by the Department of Health as an approach for facilitating the social inclu-

### Intensive Interaction basic techniques

- Tuning-in
- Enjoyment
- Holding back, observing and waiting – don't do too much
- Allowing the person to lead, 'go first' or take the first turn
- Responsiveness - responding using imitation and joining-in and in other ways
- Being relaxed and unhurried
- Pausing
- Timing responses
- Positioning and available look

10

sion of people with severe or profound learning disabilities in Valuing People Now: a new three year strategy for people with learning disabilities (DoH, 2009). In this strategy document Intensive Interaction is recognised as an approach for '... facilitating meaningful two-way communication' for people with complex needs (p.37) and specifically identified in 'Intensive Interaction: developing meaningful two-way communication' (p.38).

Intensive Interaction also concurs with current National Institute of Health and Care Excellence (NICE) Guidelines for supporting children and adults with autism spectrum disorder [NICE - CG170 & CG142], for the prevention and interventions for people with learning disabilities whose behaviour challenges [NG11], and for the prevention, assessment and management of people with learning disabilities who suffer from mental health problems [NG54].

More specifically these guidelines point services and staff to consider sensitive and responsive 'psychosocial' and/or 'social communication' interventions that address 'the core symptoms of autism' [CG170, p.19 & CG142, p.24] in order 'to increase joint attention, engagement and reciprocal communication' [CG170, p.20] as Intensive Interaction is evidenced to do.

In terms of interventions for people with learning disabilities whose behaviour challenges, NICE points services and staff to develop Positive Behaviour Support strategies aimed at developing 'improved communication, emotional regulation or social interaction' for and with the person [NG11, p.19 & p.29], fitting well with the Intensive Interaction rationale and evidenced outcomes.

Finally, when addressing the mental health problems in people with learning disabilities, NICE points services and staff to 'focus on developing communication and social functioning skills' (NG54, p.22), again a good fit with the use of Intensive

Interaction.

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# The Clubhouse

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Dr Claire Smith

ST6 Trainee

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*Tower Hamlets CLDT*

*Claire Smith, ST6 Psychiatry, specialising in Intellectual disability, recounts an experience working in New York's Hells Kitchen in the 1980's which amongst other things, enabled her to be active in recovery for people with mental illness. This experience shaped her interest in psychiatry which ultimately led to her upcoming ID consultant role.*

With its distinctive green door and Georgian façade, Fountain House Clubhouse<sup>1</sup> became known in the local community as the 'Georgian mansion on 47<sup>th</sup> Street'. Not a millionaire's city pad, but a Psychiatric Rehabilitation Programme.

Established in 1948, Fountain House can be found in a street of brownstone buildings, lined with Ginkgo biloba trees, in midtown Manhattan, NYC; in an area once known as Hell's Kitchen.

During the summer of 1987, I flew to New York to work as a Volunteer at Fountain House on an exchange programme organised by the 'Winant Clayton Volunteer Association'.<sup>2</sup>

Knowing very little about mental health at that time, I passed through the door of Fountain House not knowing what to expect and was totally unaware that New York City would become my home for the next 6 years. It would also mark the start of a career in Mental Health and Psychiatry that has spanned 27 years.

I clearly remember my first tour of Fountain House, given by a member (client), Ronny. He greeted us warmly and guided us around the programme introducing us to people busy working on a diverse range of projects. Whether the work involved getting the weekly newsletter published or preparing the lunch, I had difficulty distinguishing staff from members. There was an air of collegial warmth, collaboration and respect throughout. A sense of celebration was evident everywhere with photos of members who had received educational qualifications, worked on Transitional Employment Placements and/or had secured Independent work.

Our tour took us through two five storey buildings visiting each work area along the way. Work areas are called Units and included: Housing, Clerical, Research and finally the

Snack Bar on the fifth floor with panoramic views across Mid Town Manhattan toward the Empire State Building and beyond. Members and Staff who we met on the tour asked 'are you a Clayton?' We soon realised that the Clayton volunteers who arrived every summer from the UK had quite a long history at Fountain House.

The following is an extract from the WCVA website: *'The Winant Clayton community service programme grew from the World War II dreams of two extraordinary men; John G Winant who was the US ambassador to Britain and The Reverend Phillip (Tubby) Clayton the private chaplain to the Queen Mum, founder of Toc-H and former Vicar of All Hallows-by-the-Tower.*

*All Hallows had been badly damaged by bombing, as had other churches and community centres in East London. The area was in desperate need with much poverty and social deprivation. Tubby wanted help for the East End in both cash and kind and John Winant agreed to help him find young Americans to come to London to assist him voluntarily, and so it started. Ten years later in 1959 British volunteers were invited to America to do similar work and the summer exchange began. Obviously Winant Clayton has moved with the times but the essential spirit of the scheme remains the same.'*

My experience as a volunteer provided an opportunity to become a part of the extraordinary community of Fountain House whose culture promotes the building of therapeutic relationships through the medium of work, enabling recovery. I found a culture that reflects respect and dignity and provides opportunities to acquire skills, confidence and self esteem enabling individuals with severe and enduring mental health problems to build a future through employment, educational and social opportunities both at Fountain House and in the larger community.

After completing my summer volunteer post I returned to Fountain House as an employee, developing and directing the 'Horticulture Unit'; engaging members in all areas of work for the benefit of members, staff, and visiting colleagues from around the world. The Unit also made regular group visits to High Point Farm, New Jersey bringing back produce from the garden to Fountain House where it would be prepared and served in the Kitchen-Dining unit and Snack Bar.

I had many interesting roles and experiences whilst working at Fountain House including: encountering, at close quarters, a brown bear. I was driving from High Point Farm to New York City, with colleagues from Arkansas, along a heavily forested single track road, when the bear strolled out into the road ahead of us. I was reliably informed by my

colleague from Arkansas that the bear was young, probably 4 years old. During future visits to the farm I saw other brown bears but never that close.

Other experiences involved training and supporting Fountain House members on a number of job opportunities around New York City. These diverse, part time, time limited, supported work opportunities that pay the going rate for that job, are known as Transitional Employment Placements. Supporting members on these jobs took me all over the city including the offices of Dow Jones, then situated in the Twin Towers, at the heart of the financial district. It was there I trained Fountain House members to become indoor messengers and to work in the companies wire room.

Group placement opportunities existed for those needing more on-the-job support. Every Wednesday a group of 12 members and I would make our way to the meat packing district; now better known for the High Line<sup>3</sup>. A freight elevator took us to the third floor of a large ware house to the premises of a company called Hoffritz. Here a team of members placed price tags on high end scissors, nail clippers and knives. Some of the most disabled members were able to access work through this group placement with a staff always on site for support. This must be my most rewarding experience at Fountain House; seeing members' work, maybe for the first time in their lives, developing skills and taking on different roles within the team.

Clubhouse colleagues, both members and staff, from around the world visit Fountain House regularly.<sup>4</sup> They typically spend three weeks learning about the Clubhouse model its philosophy, values and the 36 Clubhouse Standards which underpin the Clubhouse model. Following training Colleagues take their new found knowledge and experience back home to begin or continue their journey in building a Clubhouse community supporting the recovery of people with mental health problems.

This International Clubhouse community is supported by an organisation called 'Clubhouse International'<sup>5</sup>. Shortly before the launch of 'Clubhouse International' I returned to England to become the director of Bridge House Clubhouse; one of an International network of 330 Clubhouses found in 34 countries, providing a bridge to recovery for over 100,000 members each year.

My role on the faculty for Clubhouse Development also gave me insight into how the Clubhouse model could successfully be adapted to other cultures. Although my experience carrying out accreditation visits was limited to Europe and North America, Clubhouses are found all over the world including: Australia, Korea, Russia, South Africa, Canada, Sweden, USA and France.

One of the most enjoyable roles at Bridge House was developing a network of employers in the local community that offered our members Transitional Employment placements<sup>6</sup>.

The decision to become a Psychiatrist came relatively late in life, after a very full and rewarding career working in the Clubhouse model. Although my work is very different now, over the years I have remained in contact with my Clubhouse colleagues in New York and the UK. During my medical training I have found opportunities to make a number of presentations

to my Psychiatry colleagues jointly with members and staff from Mosaic House Clubhouse, South London.<sup>7</sup>

In 2008, for part of my medical elective, I returned to New York City to work at the 'Store Front', Centre for Reintegration, on 49<sup>th</sup> Street between 8<sup>th</sup> and 9<sup>th</sup> Avenues.<sup>8</sup> The office was staffed by three part time administration/receptionists (all members of Fountain House), a Psychiatrist and a General Medical Practitioner. The Store Front runs a number of projects including: the Rehabilitation Alliance, the Manhattan State Project and the 'CAMP' research study comparing the side effects of a number of atypical antipsychotics.

When I returned to New York City for my elective in 2008, the Fountain House neighbourhood 'Hell's Kitchen'<sup>9</sup> known for its street crime, drug and gang culture had been transformed. The area is now called 'Clinton Community'. As a volunteer in the 80's, on a hot and humid evening, I recall gathering with families from the community in the local park to watch the movie 'The Colour Purple'. The park, on the corner of 9<sup>th</sup> Avenue and 47<sup>th</sup> Street, frequently used by drug dealers and addicts, was full of people wanting to reclaim the park for their families. The park is still there but now has a children's play ground and beautifully tended gardens.

My relationship with the WCVA began again in 2014 when I became a trustee. Winant volunteers from America arrive during the Summer to take up posts in a number of different projects in London. *An excerpt from a recent volunteer and the full article can be viewed on the online version.*

For more information regarding opportunities for internship or volunteer work at Fountain House contact Dr Claire Smith ST6 Psychiatry ID; email: [c.f.smith1904@gmail.com](mailto:c.f.smith1904@gmail.com)

#### References and further information:

1 <http://www.fountainhouse.org>

2 <http://www.winantclayton.org.uk>

3 <http://www.thehighline.org>

4 <http://www.fountainhouse.org/blog/colleague-training-how-we-do-what-we-do>

5 <http://www.iccd.org/about.html>

6 Publication for International Centre for Clubhouse Development (ICCD): Corcoran J, Forman R, Skokan P, Tompkins E, Hänninen J and Multanen S, et al. Transitional Employment: An International Right of Membership. The Clubhouse Community J. 2002 August; 4: 97-100

7 <http://www.mosaic-clubhouse.org>

8 <http://www.reintegration.com/about-us-1>

9 [https://en.wikipedia.org/wiki/Hell%27s\\_Kitchen,\\_Manhattan](https://en.wikipedia.org/wiki/Hell%27s_Kitchen,_Manhattan)



# 'Summer in the Forest'

**Dr Rachel Lee**

**CT2 Trainee**

*West Midlands*



Summer in the Forest is a documentary; directed by Randall Wright about people with learning disabilities living in a community home called L'Arche in Trosly-Breuil, northern France. It was screened at the MAC in Birmingham on 27th and 28th June 2017 and other screening dates were available nationally across the UK over the summer of 2017; which can be found on their website: <http://www.summerintheforest.com/>. Although these dates have now passed there is an option to buy and download the documentary on their website.

L'Arche is a community was founded by the Canadian-born Catholic author and philosopher, Jean Vanier. He is now aged 88, and served as a young officer in the British Royal Navy. He was stricken by the horror of the Second World War and Nazi death camps that he felt a calling to do good. It was here in the 1960s where a priest showed him the grim conditions in which people with learning disabilities were housed. Stricken by the loneliness he saw in this place, Jean was compelled to do something. This documentary then goes on to introduce the characters Philippe, Michel, Andre and Patrick, who were labelled as 'idiots', and locked away, forgotten in the violent asylums, until Jean took a stand and secured their release by inviting them to live with him in his cottage. Over time, more were added to their community and they soon established L'Arche, meaning 'The Ark'; with its focus for men and women who would otherwise live locked up, can now live as family, and it is a family filled with unusual joy as can be seen in the documentary. It is through living here that Jean has learned 'what it is to be human, to be foolish, and to be happy', which he feels most of us have forgotten.

This documentary is light, sometimes comedic, but also emotionally challenging. It is mainly narrated by Jean himself, describing the lives before and after for his L'Arche residents. One striking phrase that speaks to us having worked in inpatient units was by Philippe, 'In the psychiatric hospital, there was nothing to do...when some lads misbe-

haved, they were given injections to calm down. It was quite a relief to be out of there, I can tell you'.

We see that each person has many interests, and they would be supported by their volunteer carer to embark on these. However what makes the viewer smile inside is them all sitting around the dinner table and they are 'having fun and celebrating their meal together in their own way, and you will see that one or two people will be prodding each other with forks', yet that adds to the feeling that 'that's life' amongst the joy.

Fundamentally we are taught that people with disabilities have been pushed down in society, and they do not know that they are human beings and lovable, and have a purpose. This community allows them to continue with their interests, have needed support and enjoy living. One thought which came from this, is that the current philosophy in social services is 'care in the community' and that people with learning disabilities should not live in homes, but in their own flats independently (1). With this, Vanier was able to explain that this had been trialled in the beginning, and these people got jobs and their own living space, but they also found that beer and television went well together, and he needed to help them through issues with alcohol dependence. He then explained that sometimes the point is to not just have independence, but it's to have friends, and 'people belong together in a shared life'.(1)

Counter to the positive themes from this documentary, there was space for the topic of loss, which these people know and have experienced. When going on to discuss this, Jean states that there is a beauty in loss or suffering, this is a time for people to come together as a community. Finally, Jean explains towards the end describing today's society, 'we've created an identity of power and not an identity of relationships, and that's what the whole film is about – an identity of relationships.'

### Reference

<https://www.spectator.co.uk/2017/07/jean-vaniers-world-of-love-and-kindness/> [accessed 22/11/17]

## Upcoming conferences

<u>DATE</u>	<u>TITLE</u>	<u>LOCATION</u>	<u>ORGANISATION</u>	<u>COST</u>	<u>CPD points</u>
<b>MEETINGS</b>					
20.04.2018	<a href="#">Faculty of Psychiatry of Intellectual Disability Spring Conference</a>	21 Prescott Street	RCPsych	RCPsych and BPS members rate*£110  Reduced Rate£55  Non-Member £150	6 CPD hours per day
10-11.05.2018	<a href="#">Child &amp; Adolescent Intellectual Disability Psychiatry Network (CAIDPN) Conference</a>	Windmill Village Hotel, Golf Club and Spa, Birmingham Rd, Allesley, Coventry CV5 9AL	CAIDPN	£40-50  Bursaries available	TBC
24.05.2018	<a href="#">Special Interest Group in Neurodevelopmental psychiatry Spring Meeting</a>	Metropole Hotel, Leeds LS1 2HQ	RCPsych	Standard fee £90; Reduced rate £50 (CTs & retired); Medical Students £25	6 CPD hours per day  [Posters are invited with a prize of £75 (No fee for medical students submitting a poster) ]
04-05.10.2018	<a href="#">Faculty of Psychiatry of Intellectual Disability Annual Residential Meeting</a>	Marriott Hotel, One Queen Square, Liverpool, L1 1RH	RCPsych	TBC	6 CPD hours per day

## Upcoming prizes

<u>DATE</u>	<u>TITLE</u>	<u>LOCATION</u>	<u>ELIGIBILITY</u>	<u>PRIZE</u>
PRIZES				
30.04.2018	<a href="#">Brian Oliver Prize</a>	Presented at the Faculty residential meeting, usually held in October each year	Eligible: Specialty trainees (CT1-3 or ST4-6) or consultants in psychiatry (within three years of their first consultant appointment)	<b>Prize: £500</b>  The prize is awarded for research undertaken in the psychiatry of learning disability.
31.05.2018	<a href="#">Bursary for Psychiatrists from Developing Countries</a>	Annual Residential Meeting	Psychiatrists living and working in LMIC who intend to present at the Faculty Annual Residential Meeting	The bursary will cover the cost of economy class travel, accommodation during the ARM, free registration, and attendance at the Conference Dinner, up to a maximum of £1,500 (LMIC= Low and Middle Income Country )
04-05.10.2018	<a href="#">Alec Shapiro Prize</a>	Presented at the Faculty Annual Residential meeting, usually held in October each year	Speciality trainees CT/FTSTA 1-3, ST4-6/LATs and SpRs or Members of the College in a training post	Two prizes, for best poster presentation (£150) and best oral presentation (£200)
01.12.2018	<a href="#">Professor Joan Bicknell Medical Student Essay Prize</a>	Presented at the Faculty spring meeting, usually held in April each year	Eligible: All clinical medical students in the UK	<b>Prize: £250</b>  Essay written by a medical student about their contact with a person (or people) with learning disability during the course of their studies

