

# Psychiatry of Intellectual Disability

Newsletter of the Faculty of Psychiatry of Intellectual Disability

DECEMBER 2020 Vol 22, Issue 2



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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. The Editor reserves the right to edit contributions as deemed necessary. Copyright of submissions are retained by its author, but the College reserves the right to reproduce the article on the Faculty website pages.

Please email articles to either the <u>Editors</u> (psychidnewsletter@gmail.com) or <u>Kitti Kottasz</u>, Faculty Committee Manager (intellectualdisability@rcpsych.ac.uk) by 26 March 2021 for the next issue (due Spring / Summer 2021).

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## **Editorial**







# **Editorial**



Dr Kathleen Levick

Editor

#### The Arts Edition

Welcome to the December 2020 edition of the Faculty Newsletter.

In this, my second edition as Editor, I am delighted to announce that my suggestion in my last editorial was picked up and people have run with it! That is to include a regular Arts column of reviews, opinions, experiences.

We have, in this edition, no fewer than 3 such articles, including a film review, an experience of the Amici Dance Company and a book launch - a new book about Experiences of COVID-19 in people with intellectual disabilities.

The Arts are so important to our everyday experience and joy in life, and no less to our patient population who benefit from art in the form of therapies, of creative expression, whether that be art, writing, theatre or music. This year as well, as with so many industries, the Arts have been badly hit with venues closing for large parts of the year, some never to reopen. I am so glad to bring a focus on such a threatened and needed sector.

Of course, we cannot ignore the fact of 2020; what a year! People will no doubt be glad to see the back of it, but we have already had some sobering news and figures about the burden of this pandemic carried by our patient population, as outlined in the View from the Chair from Ken Courtenay.

I want to thank all of our contributors, as ever, who are really what make this newsletter what it is. We have our regular features, with updates from Mary Barrett, Chair of the Special Advisory Committee, write-ups of some conferences (yes, even in 2020), the regular Research round up and the National ID Reps piece.

This edition heralds a change in personnel, not only in welcoming the new trainee reps, Daniel Wilkes and Amina Rawat, but also new members of the newsletter editorial team, who will start their terms with the next newsletter

officially: welcome to Jen Mutch and Jozsef Szavuj!

As much as this year has been a challenge for everyone, and though we have some hope in sight in the form of various vaccines, we are not yet out of the woods and may yet need some patience and fortitude to keep on going. Despite this, of course, life goes on. With this in mind, we have an interesting survey presented by two of our doctors into how the now common use of technology in consultations has been welcomed. We have the winning submission for the Joan Bicknell medical student essay prize and an insight into ID-CAMHS dual training in the North West as well.

As always, I do hope you will enjoy this edition. I am so glad to say that, despite this awful year, we have had a bumper number of submissions this time around and even have some saved for the next edition. I remain continually impressed at the on-going productiveness and professionalism of all my colleagues, no matter the background anxieties and stressors. Sincere thanks to all of our contributors for the fine work that you will find here within.

The team and I would like to extend our best wishes to everyone for the holiday season, wishing you a restful and peaceful time. After such a year, we need to make time to reflect on what has been and to gather ourselves for the next year the dark nights are perfect for that, for self-care and regrouping, even if it is not the festive season that we might have hoped for. But, just as the solstice heralds the journey back round to longer warmer days, so we can move forward into 2021 with optimism, armed with the knowledge and experience that even (maybe especially) hard times offer.

I will say, as always, don't hesitate to be in touch: this is your newsletter! Please do suggest any ideas or offers of news or articles. Keep looking after yourselves and each other.

Kathleen Levick

December 2020

Co-Editors:

Geoff Marston, Elizabeth O'Rourke, Indermeet Sawnhey

# View from the Chair







Dr Ken Courtenay
Chair of Faculty
of Psychiatry of ID

@psychiatryofid



As the months move on towards the end of the year, we continue to live with COVID-19. The impact it has had on people with intellectual disabilities is becoming clearer with the data on death rates by Prof. Glover of Public Health England. The death rate is estimated as three times that of the general population and deaths from all causes this year is 2.3 times that recorded in 2019. The pandemic is disproportionately affecting the people and families we support. There will come a time when we will reflect in greater depth on the full impact of COVID-19 on people with intellectual disabilities. For now however, we need to continue to care for people and guide services through what has become the greatest challenge we have faced in our working lives. (https://www.gov.uk/government/ publications/covid-19-deaths-of-people-with-learningdisabilities)

In October the Faculty convened a very successful on-line one-day conference in place of our annual two-day residential conference. Over 220 participated in the day with excellent presentations from a diverse range of speakers. Regi Alexander led on the very moving and excellent video homage to Prof. Bhaumik who sadly died in November 2019. Sab has left an enduring legacy to the Faculty in how he influenced service development and academic work that emanated from Leicester to other services across the UK and beyond.

In spite of the pandemic, the President continues to lead the College in its work under different circumstances than usual. Council welcomed the International Strategy of the College and I envisage the Faculty using it as a platform to promote our specialty globally. I would appreciate members sharing with me information on their work in teaching or service development with partners in other countries. (https://www.rcpsych.ac.uk/members/international-members/international-strategy?searchTerms=international% 20strategy)

Rohit Shankar and colleagues launched 'Step Together' a strategy for epilepsy care in people with intellectual disabilities supported by the Intellectual Disability Section of the Royal Society of Medicine in November 2020. (https://ore.exeter.ac.uk/repository/bitstream/handle/10871/123728/Step%20Together.pdf?sequence=1&isAllowed=y).

Epilepsy care is an important element in our work as psychiatrists in intellectual disabilities because of the prevalence of the disorder among the people we support. I remind you of the excellent College Reports 203, 206 on epilepsy in ID and the guidance on prescribing Valproate in women of childbearing age. (https://www.rcpsych.ac.uk/mental-health/treatments-and-wellbeing/valproate-in-women-and-girls-who-could-get-pregnant)

Looking to the future, I hope that 2021 will see a turn in the tide of the pandemic that will allow us to practice with fewer restrictions. Whatever happens, it is certain that we will learn from this time and adapt and innovate in how we deliver care. I look forward to our members continuing to connect with and support each other in 2021.

Ken Courtenay

Chair, Faculty of Psychiatry of Intellectual Disability Royal College of Psychiatrists UK

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Regular Column: ID SAC







# View from the ID Specialty Advisory Committee

**Dr Mary Barrett** 

**SAC Chair** 



As I write this column, I cannot believe that another 6 months has passed! This has made me stop and think about what we have achieved and where we are headed.

What now?

Those of you who have read my previous columns will be aware of the huge amount of work the SAC has been undertaking on the curriculum rewrite. The second stage of our application to the GMC is due in early October, making time of the absolute essence. The SAC met in September to look at the feedback from the curriculum consultation process – our curriculum certainly generated a lot of interest, with the second highest submitted number of responses, which is particularly gratifying given we are a small specialty. The findings were generally positive, with many useful suggestions. I am currently working with the Curriculum Team to update the documents in line with our discussions at the SAC, ready for a final 'once over' by the SAC before submission. Other SAC members are working on additional documentation to support the application process. In addition, I am working with the Child and Adolescent Psychiatry (CAP) SAC Chair, Dr Suyog Dhakras, and 2 trainees with experience of training in both subspecialties, Dr Solomon Shatananda and Dr Keir Jones, to map out the CAP-ID dual training documentation, which will be submitted alongside the individual curricula. My thanks to them, to all the members of the SAC and to everyone who has engaged with the feedback process for their valuable contributions. Hopefully in the next edition of the newsletter I will have good news about outcome of the GMC approval process.

What next?

At a recent Curriculum Revision Working Group, Pauline Whitelaw, the Curricula and Quality Manager, raised the issue of the SACs returning to 'Business as usual' in 2021. I commented that I couldn't really remember life before the curriculum work took over, and it turns out I wasn't the only one!

Pauline is in the process of pulling together information on the role of the SACs for when we return to business as usual and will share that with us shortly. It is clear that some ongoing work will need to continue on the curriculum alongside this, so SAC members will continue to input on this important work.

We have agreed that, as part of the review of the role of the SACs, we will review the membership lists. We will continue to have input from our trainee reps, which is invaluable; in addition I am particularly keen to have increased input from ID TPDs, given they are the ones managing education 'in the field'. Now we have the option of meeting virtually (currently the only option!), my hope is that this will make it easier for more people to participate in the very valuable work we are doing on behalf of the College. Please do contact me if you want to know more and I will update everyone further in the next newsletter.



# Regular Column: Trainees







# View from the National Trainee Representatives

**Dr Kathleen Levick** 

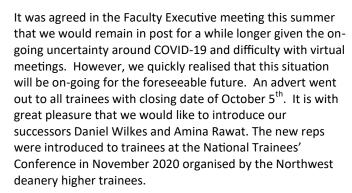
Dr Reena Hag

RH: Consultant Peninsula Deanery

KL: ST5 South London Deanery

Outgoing National RCPsych ID Faculty Higher Trainee Co-Representatives

It has been a long year for all of us in the NHS and for everybody as we have all adapted to new ways of living due to COVID -19. This has also meant some changes in the college and the faculty.



The rep role highlights of this past year have included the National Trainees' meeting with Ken Courtenay (the faculty chair) which we organised. This took place on September 3<sup>rd</sup> and was well attended, with up to 36 trainees joining from across the country (3 of the 4 devolved nations were represented); this was set up to capitalise on the newly familiar video conferencing modality to meet with as many people as possible. Many themes emerged from a long and fruitful discussion. Trainees were encouraged to make the most of their training from day one and viewing themselves as consultants in training and to make use of the flexibility and opportunities offered within Psychiatry of Intellectual Disability (ID).

We encouraged everyone to make recruitment to the specialty their business, and also to make the most of trainee networks and engagement to maintain good connections and opportunities, especially for those in more geographically remote areas, or areas without many other higher trainees (especially important during this time of pandemic/social distancing/virtual meetings etc.) The issue of more options in Dual Training was raised again; there is a clear desire for this to be expanded, though we also discussed the freedom to shape your own training and make good use of Special Interest sessions, for example. We





highlighted the opportunities within research whether that be a large or a small project; this could be accessible to all.

As trainee reps we continued to add our voice and represent trainees at the Special Advisory Committee (SAC) and the Recruitment Steering Group. As part of the Recruitment Steering group we have been involved in meetings to discuss setting up an ID faculty promotion video for the core trainees and other grade doctors, led by Dr Laura Korb; this is ongoing, with the next meeting in the New Year. There are plans for focusing on priority tasks to promote the faculty.

Another great achievement this year has been that the SAC has submitted the revised curriculum to GMC. It was agreed prior to the pandemic that we would continue our involvement with these committees after our tenure as reps, so as to finish pieces of work until an appropriate handover point. Reena has also attended the first Membership Engagement meeting set up by Dr Jaydeokar in June 2020.

We have been sharing the responsibility of maintaining contact with trainees via basecamp, Twittter @idtraineesuk and we have also set up a whatsapp group. We found that all of these were a great way to maintain connections with trainees in between virtual meetings and conferences. As reps we are eager to get any feedback from trainees across the country, good or bad, so don't hesitate to be in touch.

Kat was also tasked with administrating the Faculty of ID psychiatry presence on Facebook; again, any contributions or suggestions would be welcome, as we hand over these social media accounts to our new rep colleagues.

As you probably also know, Kat is the Editor of this newsletter since the previous edition. A number of members of the current Editorial Team will be moving on, and we welcome the two new members of the Editorial board, Jen Mutch and Jozsef Szavuj (below)!







They made their successful applications this year, and will be fully involved starting with the next edition of the newsletter.

Kat was approached to speak at a joint Newcastle and Birmingham PsychSoc conference in November; this was held virtually and in the format of 'A Spotlight on Psychiatry of ID'.

Another highlight of this year was the ID trainees' conference that was held in November, very well organised and hosted by the Northwest deanery higher trainees. The programme was interesting and engaging and provided opportunity to trainees to share their experiences and engage on a national level. This also provided a great opportunity to meet with trainees from all the four nations through the network meeting towards the end and also introduced our new trainees' reps, Daniel and Amina. We are sure their enthusiasm and leadership will provide a platform for all the trainees in the faculty to engage with the faculty and promote the faculty in their regions.

Many more projects are in the pipeline for this academic year, so watch this space!

We are positive and sure that Daniel and Amina will be looking forward to working with the trainees on any issues in order to support them in their projects to achieve their training needs.

We thoroughly enjoyed our time as the higher trainee reps for the past 18 months and it has been a pleasure to see some great achievements like the submission of the revised curriculum to GMC, four nations trainees meeting digitally with the chair, a great conference put together by NW trainees, as well as the faculty promotion work under the recruitment steering group, to name but a few. We have been heartened to witness the resilience among trainees during this difficult year. With all the best wishes for the future, we say goodbye and thank you for supporting us, and proudly hand over to the new reps!

# Welcome New Reps!

#### Daniel Wilkes:

Hello everybody - I'm delighted to have been chosen to represent ID trainees across the UK. At the moment I'm an ST4 working in NHS Grampian - currently at the Royal Cornhill Hospital in Aberdeen with a joint inpatient and outpatient role. I've got a lot of experience in representing trainees as I'm already a member of the Psychiatric Trainees' Committee and a Vice-Chair of the Academy Trainee Doctors' Group - which brings together trainee reps from all of the Medical Royal Colleges and Faculties. I'm passionate about our specialty and want to bring as many core trainees into our family as possible, not least to make sure that people with intellectual disabilities get the high-quality healthcare that they deserve. Please do get in touch with me if you're having any problems with your training in ID because that's what I'm here for!



#### Amina Rawat:

I commenced my higher training in February 2020 and am currently working in a community learning disability service in east London. I find it enjoyable and positively challenging to communicate with people with intellectual disability and work with multi-disciplinary teams to assess their needs and provide the best quality of life achievable for them. My interest in learning disability extends out of my professional life being a Special Educational Needs link governor at a local school. I have a special interest in service development, education and ADHD I was the lead clinician in developing an ADHD service at a London prison where I also organised the academic teaching programme.

I am keen to ensure that the voices of doctors are heard and their needs are met, at whatever grade they are in the workforce. In my previous job as a Specialty Doctor in I undertook the role as the London representative for the SAS Doctors Executive Committee at the College. I am also a mentor for

international medical graduates. I feel privileged to have now been given the role as one of the National ID Higher training representative for the Executive Committee of Intellectual Disability Faculty at the College and look forward to working with you all in this role.











# Research Roundup

#### **Rachel Steele**

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

@TEWV\_library



There are concerns about the impact of epilepsy and antiepilepsy drugs (AEDs) on bone health and an increased risk of fractures. People with ID are liable to have seizures which do not respond fully to AEDs and therefore have higher risk of fractures (Sawhney et al., 2020). A cross-sectional study found there is little evidence that people with ID and epilepsy and their carers are being informed about the risks of AEDs and fractures and how to alleviate them.

Rachel Steele, Clinical Librarian with Tees Esk and Wear Valleys NHS Foundation Trust, begins the I-Spy Research Series with a focus on Covid-19 in the context of people with intellectual disabilities.

The Covid-19 pandemic is an unprecedented and on-going world health crisis and represents challenges in the care and treatment of people with intellectual disabilities, as well as for the general population. A guideline (Alexander et al., 2020) discusses specific issues which arise for the care of people with intellectual disabilities, such as hospital passports, individual COVID-care plans, the central role of families and carers, capacity to take decisions, issues arising from social distancing, ceiling of care/treatment escalation plans, mental health and challenging behaviour and caring for someone who has contracted Covid-19 in a community of inpatient mental health setting.

### Research Round-Up

An observational descriptive case series analysed deaths due to Covid-19 in people with intellectual disability (Perera et al., 2020). 66 deaths were analysed. The mean age of people with ID who died of Covid-19 was younger than the general population. High rates of moderate-to-profound ID, epilepsy, mental illness, dysphagia, Down Syndrome and dementia were reported.

A questionnaire was sent to UK psychiatrists working with adults with ID on the success and challenges regarding withdrawing antipsychotics for challenging behaviour. Half of the 88 respondents indicated that they started withdrawing antipsychotics over 5 years ago and 52.3% indicated that they are less likely to initiate antipsychotic treatment since the launch of STOMP. However, following STOMP, 46.6% are prescribing other types of psychotropic drugs (particularly antidepressants) instead of antipsychotics (Deb et al., 2020).

UK government policy is for people with ID and/or autism to move out of hospitals back to their homes and Cornwall implemented this policy in 2007. A recent study found that people with complex needs with a history of placement breakdowns and past institutionalisation can be settled safely and effectively in local communities but it is challenging for them to achieve a satisfactory quality of life long-term (Niven et al., 2020).

A recent study of death and dying in community ID services found that a major disadvantage experienced by people with ID was that their deaths were relatively unanticipated. People with ID living in supported living settings experienced poorer outcomes even when their death was expected (Todd et al., 2020).

Willner et al. (2020) compared the mental health of informal carers (mainly parents) of children and adults with ID and a comparison group of parents of children without disabilities. They found that carers of both children and adults with ID had significantly greater levels of a wish fulfilment coping style, defeat/entrapment, anxiety and depression.

A recent qualitative study reported that trauma may have a serious impact on individuals with ASD and ID and that multidimensional, individualised assessment strategies may be required to recognise PTSD or trauma-related symptoms in this group (Kildahl et al., 2020).

A cross-sectional study investigated the extent to which older community-dwelling people with ID were living with comorbidities in Australia. Findings indicate that these people had considerable comorbidities, including arthritis, diabetes, cardiovascular diseases, asthma, carcinomas and mental health conditions (Hussain et al., 2020).

A diary study considered the extent to which adults with Down Syndrome are engaged in leisure activities. Findings show that most of the adults did not meet recognised physical leisure activity intensity recommendations and did not exceed levels of passive leisure in the general population. Suggestions are given for how to increase leisure participation in this group (Mihaila et al., 2020).

A qualitative study examined the experience of ex-offenders with ID after release from prison. Overarching themes emerged to encompass their experiences. These were the difficulty of staying out of trouble, the importance of family and the need to be the "tough guy". In general, participants were under-supported following release of prison (Chiu et al., 2020).



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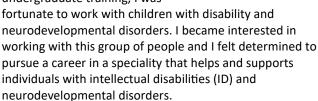


# Dual ID CAMHS Training; Health Education North West.

**Dr Solomon Shatananda** 

ST8, North West

It has been a thrilling and interesting journey from the start of my undergraduate training. Having work experience in a non-profit organisation (NGO) in India during my undergraduate training, I was



After moving to the UK and completing my foundation years, I pursued a career in Psychiatry. I was fortunate to gain experience in both CAMHS and ID. The culture and collaborative working in both these specialities caught my attention; creative solutions are appreciated. The training experience, trainers, and TPDs inspired me to apply for the dual training programme. I was thrilled to be appointed the first dual ID and CAMHS trainee in the North West of England.

My rotation so far has been in two generic CAMHS posts, one of which included in-patient experience. However, in order to gain experience of working in an in-patient specific ID-CAMHS service, I applied for a secondment to the Ferndene Unit in the neighbouring Deanery and was pleased to be given the opportunity. I was certainly amazed by the efficient inter-Deanery joint working, about which I was initially sceptical, but clear communication and planning made the process effortless.

The community CAMHS posts helped me to gain valuable skills in working in mainstream CAMHS and to explore avenues of joint working with CAMHS-ID teams. I have particularly enjoyed joint working clinics with community paediatricians in specialist schools, which was a unique opportunity.

In my training programme I spent time in two Adult ID services, one in the community ID team and another in an inpatient Forensic secure service. They gave me a wide area in which to explore my skills and gain valuable experience of working with adults with ID and comorbid complex needs. The posts exposed me to a variety of experiences such as forensic risk assessment, anti-libidinal assessment, and acquired brain injury.

I am currently in my final, joint ID-CAMHS, training post. I work part-time in the Adult ID Community Team and part-time in the CAMHS-ID Team. This is a unique experience which I hope will help me better understand the gaps between the services, with a particular focus on Transitions. I intend to

explore avenues in supporting children and young people with ID and comorbid complex needs as they move to adult services.

Both specialities lay a strong emphasis on psychological mindfulness, psychotherapy, and positive behaviour approaches. I am also pursuing an additional degree in behavioural analysis and interventions at Edgehill University, which has helped me understand Positive Behavioural support (PBS) and to be actively involved in providing a holistic treatment approach.

I completed three of my rotations in Cheshire and Wirral Partnership (CWP) NHS Foundation Trust where I am involved in research studies jointly with CANDDID (Centre for Autism, Neurodevelopmental Disorder and Intellectual Disability). I was immensely honoured to be invited to present my systematic review at the National ID Conference 2019 on 'Usefulness of current autism diagnostic or screening tools in adults with ID'. I was also fortunate to be given opportunities to present four posters on QI projects, research and audits, at national and regional conferences.

I was the Regional ID Trainee representative and the co-chair for the National ID Trainee Conference. I am a member of CAIDPN (Child and Adolescent Intellectual Disability Psychiatry Network) which has helped me shape my learning experience with the immense resources within the network. I was awarded the trainee bursary to attend the annual conference.

Working in both specialities has helped me understand better the differences and similarities in these services, the service demands versus service-user needs and thus helped me develop as an advocate in supporting people with ID.

An area of interest that caught my attention during my training years is 'transition' from child to adult services, recognised as a key agenda by the Royal College of Psychiatrists and NHS England. I am currently involved in a project on transition from a regional perspective, with a focus on service-users with ID.

These are some of the opportunities that I have had during my dual CAMHS-ID training. I believe it has shaped my personality, helping to develop my leadership and clinical skills, as well as kindling new passions in my career and professional life. I would whole-heartedly recommend trainees with an interest in neurodevelopmental disorders to consider applying for the dual training programme, as it has certainly been a rewarding experience for me.

In future, I hope to work in services that support people with ID from across the age range, with the aim of making transition smooth. I hope it will provide me with opportunities to further bridge the gap between the two similar yet differently commissioned services.







# Film Review - Crip Camp: A Disability Revolution

Dr Catriona Neil
Clinical Teaching Fellow
NHS Lanarkshire



In the midst of lockdown, I stumbled across a documentary film on Netflix which tells a remarkable story about an American summer camp in the 1970s. To quote one of the lead characters of the film: 'This camp changed the world, and nobody knows the story.' The film tells the story of the camp up to the present day and it holds some powerful messages for professionals who work with people with disabilities.

The story is told using original film footage and interviews with surviving participants, transporting the viewer back through time and space. The films starts by introducing us to a group of campers and councillors attending Camp Jened in 1971. We are told their personal stories and struggles prior to attending this free-spirited camp designed for teenagers with physical and intellectual disabilities. The campers describe the camp as a utopia, where they were accepted without judgement, as equals with a newfound sense of belonging. In this unique 'coming of age' portrayal, we observe these young people develop over time, in needing their own space, wanting more independence, relationships and their hopes and wishes for the future.

In the aftermath of the summer camp, the young people move on, but we see how the camp left an impression on them. They return to a world that treats them as second-class citizens; however, in light of their camp experiences, they were no longer willing to accept things as they were. They use their stronger esteem and empowerment to demand change, in addition to the creation of organisations to help each other as young people. Judy Heumann, a counsellor at the camp, went on to lead the fight, along with others who had attended the camp, against systems that discriminate people with disabilities. This culminated in national legislation being passed and the start of continuing the campaign for equality.

This film educates us about a minority, a group of people who are often hidden. The film encourages us to celebrate the achievements of the group, but also reinforces just how much needs to be done for people to be treated equally in an inaccessible world.

I felt there were important messages for mental health professionals working in the field of intellectual disability. This film reminds us that people with intellectual and physical disabilities may struggle to make their voices heard regarding the inequality and lack of accessibility they experience. As professionals we need to listen to people with disabilities; recognise that they have the same needs as every other individual; and support them in fulfilling their needs. When the system places obstacles in their way, we need to advocate for them, perhaps starting with the healthcare systems that we work within. We must ensure that our care is accessible, meets the needs of the people we look after and helps them grow and develop.

The film touched at my heart and left me with a feeling of hope. It shows the power of a small group of determined individuals, but also shone a spotlight on voices that often go unheard, while reminding us that much change is still needed.



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# Video-conferencing and consulting technology in NHS Fife Learning Disability Services: The use and views of staff in the context of the COVID-19 pandem-

Dr Khurram Riaz, CT3 LAT
Dr Jennifer Mutch, ST5 Psychiatry of ID

In the wake of the Covid-19 pandemic, large shifts in working practices have occurred across the NHS. One of the most significant changes has been the increased necessity for socially distanced colleague and patient contact and the resultant use of technology to achieve this.

This project sought to explore the early patterns of the use of relevant technologies and the initial views of healthcare workers in the context of a multidisciplinary learning disability service.



A survey was devised and distributed using *Survey Monkey*. Members of staff across all disciplines within the NHS Fife Health and Social Care Partnership Learning Disability Service, inpatient and outpatient services, were invited to take part. Questions elicited a mixture of multiple choice and free text responses, collected over a three week period, beginning 13<sup>th</sup> May 2020. Data was analysed using *Survey Monkey* and *Microsoft Excel*.

We refer to the use of 'video-conferencing' technology to apply to meetings with colleagues and other professionals i.e. using software such as *Microsoft Teams* and *Zoom*. We use the terms 'video-consulting/ consultation' to refer to clinical contact with patients and/or carers using video technology i.e. *Near Me/ NHS Attend Anywhere*.

## What did we find?

General usage: A total of 51 responses were received; 16 had used video technology in a community setting, 15 in an inpatient setting, 11 across both settings, and 9 in neither. Respondents comprised of 18 nurses, 9 doctors, 7 occupational therapists, 7 psychologists, 4 social workers, 2 speech and language therapists, 1 physiotherapist, 1 podiatrist, 1 clinical pharmacist and 1 who chose not to identify their professional group.





Microsoft Teams was the most frequently used software with 28.57% of respondents reporting use '>4x/week' and 46.94% '1-4x/week'. The most commonly reported reason for using video technology was team meetings (84.31% of respondents having used it for this purpose) followed by large group meetings e.g. Grand Round, Division meetings (41.18%). Webinars had been attended by 29.41% of respondents. Less than a quarter of respondents had used video technology for patient/carer interactions (Figure 1).

Figure 1. Number of respondents using video technology by activity (Total n=51)



Other: Project meetings, professional discussions (ranging from one-to-one to multidisciplinary team), adult protection meeting, supporting patients to speak with their families, meeting with service provider staff, peer group meetings, mentoring/supervision.

Contacts with patients: Respondents noted that direct assistance from a carer was required in the majority of interactions with patients (66.66% 'sometimes' or 'every time'). 70% of respondents reported successful patient engagement either 'every time' or 'sometimes'. In 25% of contacts respondents felt that the patient was 'not at all' able to engage.

Technical aspects: Easy access to the required equipment was reported by 76.47% of respondents, and 60.78% were satisfied with the quality of call when considering recent video interactions. Of the 35.29% who were not, primary concerns highlighted were variable audio and video quality and internet connectivity issues. Most (64.71%) felt able to contribute as they would in a 'face-to-face' meeting, however many raised concerns relating to the loss of nuances in communication undertaken via video technology, concerns about talking over each other and there being less depth to discussions. Several noted that it was more difficult to contribute to larger meetings using technology.

General views: Despite these concerns, all of those who had used video technology felt that the objectives of meetings were met (92.16% of respondents) and most (72.55%) would like to see continued use of video technology after Covid-19 restrictions are relaxed. Examining the free text responses in more detail, the main advantages of using video technology identified were: more efficient use of time; reduced travel expenses; enabling attendance at meetings involving individuals based across multiple sites; and increased flexibility in service delivery. Several highlighted a wish to see continued use of video technology for professional interactions but noted suitability only for some patient interactions. All of those who provided reasons for not wishing to see continued use highlighted concerns around the loss of direct contact with patients and the impact of this on building relationships and assessing presentations.

#### What else did people report?

Changes in practice have resulted in the necessity for rapid adoption of, and adaptation to, a new way of working; as expected, the majority of respondents had not used video technologies in their work prior to the pandemic (58.82% for videoconferencing and 82.35% for video-consultation).

Several key themes were highlighted in free text responses provided. Some respondents noted the particular usefulness of video technology in professional and team meetings and for contacts with carers and support staff. Triage of referrals was also identified as an area where its use may lead to a more efficient service response. It was noted that patients and carers may not have access to the necessary equipment for video-consultation, and that use of these methods of

consultation should be flexible, guided by the needs and preferences of patients and carers wherever possible. The need for funding to ensure adequate hardware, and its maintenance, was also highlighted.

Many respondents felt that the use of video-consultation was not suitable for all patients, or all types of assessment, and should not replace face-to-face contact. Hearing and/or visual impairments were noted as particular barriers to this form of communication, though it was noted to be helpful for those finding communication with staff wearing face masks particularly challenging. The important issue of confidentiality for patients accessing video consultation from a group living setting was highlighted by one respondent, noting particularly that the lack of a confidential space may preclude sharing of important information pertaining to risk.

#### What now?

The maintenance of clinical services will require continued use of video technologies, at least for the foreseeable future, and likely longer term in some capacity. Most respondents in this survey would like to see its continued use for some aspects of their work once pandemic-related restrictions are relaxed. Advantages and disadvantages of video technology are noted.

Exploration of patterns of use and the views of staff across the wider Learning Disabilities Managed Care Network is planned. Investment in appropriate hardware and software is likely to be necessary and unmet training needs should be explored and addressed. Understanding the experiences of patients and carers would also be highly valuable; additional support may be required in order not to disadvantage them in their ability to access services as we continue to adapt to the pandemic.

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## Article







# Experience: Growing into the role of pastoral care giver.

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Dr Mark Spurrell, Special Interest: Medical Education, Pennine Care NHS Foundation Trust

Prof Nihal Fernando and Dr Roshelle Ramkisson



In my leadership role in medical education I have been grateful to have the opportunity to closely work with the medical education team to provide understanding around psychological safety and pastoral care among junior trainees and senior educators. I was involved in a number of projects, workshops and away days for trainers and educators to increase the awareness of their roles and responsibilities and to improve their confidence in recognising junior trainees in need.

In this article I will be uplifting some major themes and contributions towards pastoral care, knowing these may stimulate a meaningful discussion and change of culture both for trainees and trainers.

Psychological Safety and Pastoral care can be defined as "being able to show and employ one's self without fear of negative consequences of self-image, status or career" (Kahn 1990, p. 708). In psychologically safe environments, team members feel accepted and respected. It is also the most studied enabling condition in group dynamics and team learning research.

Psychological safety has been an important discussion area in the field of psychology, management, healthcare and behavioural management. Results from a number of empirical studies conducted in various regions and countries show that psychological safety plays an important role in workplace effectiveness (Edmondson and Lei, 2014)

Psychological safety benefits organisations and teams in many different ways. The following are the most widely empirically supported consequences of a team being psychologically safe:

- Improves likelihood that an attempted process implementation will be successful
- Increases amount members learn from mistakes
- Boosts employee engagement
- Improves team innovation

As an ST Trainee, when I reflected on my journey as a junior trainee, considering I have worked in very busy environments • with different teams, specialities within psychiatry and considering my less than full time (LTFT) status in Core

training my overall period of training was longer than the usual time. As a trainee in new placements we can quickly be drawn into work. A positive aspect of this is we learn by doing this and stretch our abilities and confidence, whereas a negative aspect is that our own very busyness sometimes keeps us from having time to step back and reflect how we are doing and which areas of training we may wish to nurture.

A question always comes to my mind:

As a coach or mentor, how do we deepen and mature in our way of supporting individuals carrying out their roles with peace and dignity in time of needs?

Most important of all, we need to know when and how to seek help and provide help to others.

In my Leadership role in Medical Education I participated in themed workshops and away days, bringing everyone together where educators were both didactically and experientially learned and explored new ways of responding to situations where trainees are in need.

The aim of these workshops was to create an understanding around Pastoral care needs and creating a caring community which effectively meets the academic, social and emotional developmental needs of trainees.

The number of concepts explored to improve psychological safety for junior trainees were to:

- Help them to develop an understanding of what pastoral care is and how we provide it for our juniors, whilst supporting and caring for each other as trainers
- Increase our awareness of our roles and responsibilities in relation to pastoral care as educators and trainers
- Improve our confidence in supporting individuals who require pastoral care and alleviate any personal concerns we may have in relation to this.
- Providing the right support to make this journey smoother

A number of issues were identified that may require support measures include the following:

- Personal issues: bereavement, relationships
- Health issues: pregnancy, stress, depression, addiction
- Professional issues: disciplinary matters, regulatory authorities, licensing bodies
- Overseas trainees: language courses, getting children into schools, housing
- Confidence building: presentation skills
- Bullying or harassment
- Temporary removal of trainees in difficulty from oncall rotas
- If required referral to in-hospital counselling service; professional medical or psychological support, including psychotherapy for medical professionals.

The development of a buddy system, regular meetings with senior colleagues or mentors enables formal and informal feedback from mentor have been important in establishing pastoral support among our trainees.

The medical education team is making a huge effort to create a nurturing and supportive environment for trainees and junior doctors by involving senior educators and having this understanding not only beneficial and applicable for individuals involved but it is having a huge impact on patient's care and as a whole it is reflected at an organisational level.

Reflecting on my own journey and use of different theories in different situations and levels of training, has helped me to modify my approach towards difficult situations. I believe my leadership journey in medical education has not only focussed to improve understanding of my own needs but also has helped me to support my colleagues to understand their difficulties and getting them the right support and help at the right time. Bringing everyone's attention on the significance of Psychological safety and pastoral care and its effects on patient care, trainee's wellbeing and recruitment/ retention is vital. This is only possible by uplifting their motivation and insight towards pastoral care and wellbeing and to improve and learn from experiences for a positive outcome.









## **Book Launch**







# The experience of COVID-19; Stories from people with Learning Disabilities

Peter Cronin, Self-Advocate

Steve Hardy, Oxleas NHS Foundation Trust

Christine Koulla-Burke, Foundation for People with Learning Disabilities

David Mahon, Foundation for People with Learning Disabilities

Matthew Roberts, Post Graduate Occupational Therapy Student, Cardiff University

**Professor Edward Chaplin, London Southbank University** 













Peter

Steve

Christine

David

Matthew

**Eddie** 

On the 29<sup>th</sup> October 2020 a free book was launched at London South Bank University, it's entitled:

'Peter and friends experience of covid-19: for people with intellectual or learning disabilities and/or autism'

Peter and Steve met up in April 2020 and Peter explained what a difficult time he had over the last month.

Peter lives by himself, but receives several hours of outreach support twice a week and attends meetings at Lewisham Speaking Up, a self-advocate group.

Outreach suddenly stopped mid-March and Lewisham Speaking Up started to have their meetings on Zoom, but Peter didn't have a laptop, tablet or smart phone.

He normally attends three classes at adult education, these were all stopped.

He has three part time jobs, in the Co-op, in a cake shop and as a cleaner at the offices of a supported living organisation. He was made redundant from two of these jobs, but still works at the co-op and has done so since the lockdown finished. So, like many of us his life was turned upside down by the arrival of covid-19. The only real difference between Peter and 65 million of the UK population is that he has a learning disability and he cannot read.

We had a discussion that there must be so many people in the same position and Peter wanted to hear their stories. So, we came up with the idea of writing a book.

We spoke to Eddie at London South Bank University, who has proven record of publishing; we also approached Matthew who used to work in Abbey Wood and is always enthusiastic and positive.

Then we found out that Christine and David from the Foundation for People with Learning Disabilities were also collecting stories from people with learning disabilities.

So, we had a group of co-editors!

We started to advertise on social media that we wanted to hear stories from people with intellectual or learning disabilities and/or autism. The response we received was phenomenal.

We gave no guidance other than the length of the story and not to use any profane language, especially when writing about politicians. We received 45 personal stories from people with learning disabilities, several from families and 30 stories from health and social care organisations. The book also has a chapter about what is covid-19, what you should do to protect yourself and what lessons have we learnt from this pandemic.

The book is now an international publication. We have stories from across five continents, including Australia, Austria, Canada, England, Germany, Ireland, Malaysia, Netherland, Scotland, Spain, South Africa and Wales.

Here are some stories from the book:

This story is from Andy in England, who actually took the time to hand write his story:

In Look Dan V WANT IN THE WEEKE
IT WAS HAD AND MOT ESBY
NOT SEEN MY FRENDS
BULL I HAD LOES OF
HUMP GET MY SHOPING
IN LOST PENN
I PIND IT HOST PENN
I PIND IT HOST WENT
WONC YOU NON
BULL I HOD TO FACE IT
MY SPORT WOKET

DID O LET FOR MY
AND IT WAS NOT GOOD

LONG SAD TO SEE NURSES
DID AS WALL

'I lost two good friends in lockdown. My support workers did a lot for me and it was not good to see many people die. It was sad to see nurses die as well'



This is part of Michyle's story from South Africa:

'When I heard about the number of people dying from covid-19, it made feel really depressed. I feel like it's holding me back. I don't know how far it will spread.

When will lockdown end?'

We believe that this book really shows how resilient people with learning disabilities are. We have read some really positive stories, where people go shopping for their neighbours and give their friends a telephone call to check everything is ok. It has been a privilege reading all these stories and we are looking to forward to sharing them with you.

The book will be available from <a href="https://www.learningdisabilities.org.uk">www.learningdisabilities.org.uk</a> and <a href="https://www.stevehardyldn.com">www.stevehardyldn.com</a>

## Conference watch







# CAIDPN Conference – 5th-6th November 2020

# (Child and Adolescent Intellectual Disability Psychiatry Network)

Dr Lizzy Donaghy ST4 CAMHS-ID Northern HSC Trust, N. Ireland



CAIDPN is a network of psychiatrists who work with children and

adolescents with intellectual disabilities. CAIDPN has run an annual conference over the past two decades with conferences increasing in size year to year. This year's conference was co-hosted with the all Ireland ID-CAMHS network, a multi-disciplinary network of professionals who work with young people with intellectual disabilities across the island of Ireland. Originally scheduled to take place in Belfast, the conference was required to be delivered virtually due to Covid-19 restrictions. I was in the fortunate position to gain a bursary from CAIDPN to attend.

The theme of the conference was 'Back to the Future'. This means reflecting on and learning from past mistakes and successes, to look forward to develop better services for children and young people with an intellectual disability. (Unfortunately due to Covid restrictions Belfast was not able to showcase its famous connection to the DeLorean car in person which would have been rather fitting with the conference title!)

The conference opened with the keynote speaker, Dame Christine Lenehan, Director of the Council for Disabled Children, National Children's Bureau, and author of 'These are our children' (January 2017; commissioned by the Department of Health). This was a hopeful, encouraging and inspirational talk by a fierce advocate for children and young people with special educational needs and their families.

The talk began with an update on the SEND review announced in September 2019, and the Autism Strategy. Dame Lenehan reflected on the ongoing need for a multiagency approach for our children, the central importance of education in children's lives, the delivery of care in a personalised way, and the importance of early intervention.

She reflected on the impact of COVID for our children; including fear of illness, further isolation, loss of routine, trauma of losing loved ones, lack of certainty, issues surrounding accessing education and care, and loss of opportunity. This has of course been associated with immense family pressures and has also impacted on

parents' and carers' mental health. She focussed on human rights and reinforced that 'a COVID world should not undermine young people's and their family's rights'. She cautioned that our children must not become less visible due to COVID.

She also looked to the future when reflecting on some positive changes for moving forward, including the innovative use of virtual working and the development of the NHS Long Term Plan and the community keyworking model. We continually need to look forward - to focus on safeguarding, family work and respite, how to integrate solutions and new ways of working moving forward; to make sure the right care is delivered by the right person in the right place at the right time.

The second talk was delivered by Dr Noelle Blackman, Chief Executive from Respond. Respond is a trauma informed organisation supporting the lives of people with learning disabilities and autism. Reflecting the conference theme, this talk centred around acknowledging the trauma faced within the system failures when reflecting back on mistakes.

Dr Blackman shared the results of a study about trauma in families, commissioned by NHS England/Improvement. She discussed traumas experienced by families including the experiences of feeling unable to navigate complex systems, feeling not listened to, feeling not being seen as a whole family. They found a correlation between the journeys that families make from diagnosis and through the healthcare system and the levels of trauma experienced. The study also found that families found trauma-informed psychotherapeutic interventions helpful.

Dr Blackman discussed how we can change systems and processes to stop trauma from happening through trauma-informed practices, personal agency, collaborative working, true co-production with families, and work influencing government policy.

Dr Roger Banks, National Clinical Director for Learning Disability and Autism in NHS England, delivered the following talk which was entitled 'Time to Think'. The title was in part reference to how the pandemic has forced changes in the way we work and that now is a good time to reflect on these changes and build upon successes of these.

As a psychiatrist with an interest in psychotherapy and a founding member of the Institute of Psychotherapy and Disability, Dr Banks gave an opportunity to reflect on current practices including viewing behaviours as 'challenging' and re-framing these as 'adaptive' and 'functional', to understand the patient and their experience, and to look at the dynamic nature of 'challenging' behaviour, how the behaviour interacts with the reaction to this behaviour.

Dr Banks gave a fascinating psychodynamic perspective to examining the way we work, a perspective that can provide another tool to evaluating and building our services for the benefit of our patients.

Dr Kevin Mitchell, Associate Professor of Genetics and Neuroscience, Trinity College Dublin, opened the afternoon session with a talk entitled 'The Messy Reality of the Genetics of Neurodevelopmental Disorders'. This was an informative talk which included details of polygenic inheritance of neurodevelopmental disorders, the 'noisy' reality of how genetic mutations are expressed, and the benefits and limitations of the future of genetics in the future delivery of services. He discussed ongoing developments in genetics including the future of whole genome mapping. Looking to the future, clinical implications could include genetic diagnosis, personalised medicine and the potential for new therapeutics.

The day's final presentation was delivered by Professor Christopher Gilberg, Professor of Child and Adolescent Psychiatry, Gilberg Neuropsychiatry Centre, University of Gothenburg, Sweden. Looking back, Professor Gilberg has led a huge body of groundbreaking research in neurodevelopmental disorders. Looking towards the future, Professor Gilberg has also been a progressive voice, whose body of work has encouraged clinicians to re-think the delivery and care of children with neurodevelopmental disorders. The title of the presentation was 'From Autism' to ESSENCE and beyond' and Professor Gilberg outlined the ESSENCE (Early Symptoms of/Symptomatic Syndromes Eliciting Neurodevelopmental Clinical Examination) framework when looking at the overlapping and interacting presentations of neurodevelopmental disorders. He challenged us as clinicians to consider the whole child with robust assessment and investigation. His talk included reports from his vast array of research including the Bergan Child Study 2006 which found a high prevalence of autistic symptoms in 'typical' children. He asks: 'Typicality presupposes that there is such a thing as typical development. Is there?'

Following his talk there was a collective discussion about the importance of collaboration between different services and breaking down barriers between different specialties, and how this must influence commissioning processes. This was a theme that ran throughout the conference.

The day ended with closing remarks from Siobhan Rogan, part of the organising committee of all Ireland ID-CAMHS network and who is currently working in the Northern Ireland Department of Health assisting development of learning disability policy. She reflected on the common themes of our personal responsibility to act as leaders and advocate for the children we care for, to accept and learn from mistakes in the past, to work together with traumainformed practice, and to look to the future together.

On the second day of this virtual residential conference, the CAIDPN AGM took place, virtually for the first time. A variety of updates and topics were discussed, including an update regarding membership of CAIDPN and an update of CAIDPN activity including input into the CAP and ID executive faculties, involvement in RCPsych statements, BACD, and NHS England/Innovation planning; in addition input into multiple projects (including development of an E Textbook) and research studies. The ongoing peer support element of CAIDPN was discussed, highlighting the platform for members for forum discussion, support and advice through the Basecamp app. The meeting gave an opportunity for an update from developments across the UK four nations and internationally.

There was an exciting discussion surrounding the future of CAIDPN given its increasing membership numbers, visibility and influence. Further consultation will be held following the meeting to determine this.

Following the AGM there was an interview with RCPsych Lifetime Achievement Award winner 2019 Professor Roy McClelland by Dr Claire McKenna, interviewing editor for BJPsych Bulletin. As Dr McKenna commented, Professor Roy McClelland is an apt person to reflect back on progress in psychiatry particularly human rights. Prof McClelland reflected on his early life and education and the journey of witnessing and influencing change throughout his career. He spoke about the influence of the Bamford Review and how this has shaped the cultural landscape of care for individuals with ID in Northern Ireland moving forward into the future.

The conference ended with a virtual meet-up for CAMHS ID trainees across the UK. We discussed recruitment and different training paths, and our roles in advocating for CAMHS ID training as an exciting area to specialise.

As an ST4 dual trainee in CAMHS/ID this was a fascinating and inspirational first CAIDPN conference for me to attend. Tying in with the conference theme 'Back to the Future', I am excited to be part of a network of such enthusiastic and visionary psychiatrists, and look forward to seeing how services and care for children with ID are shaped in the future. And as an advocate for CAMHS ID psychiatrists I would encourage any other trainees with an interest in this specialty to gain experience in this area.



# Prof. Joan Bicknell Medical Student Essay prize-winner







# Experiences of Healthcare for People with a Learning Disability

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RCPsych Psych Star 2020



#### **Introduction**

It is estimated that 1200 people with a learning disability die avoidably in hospital each year—21 people a week; 3 people a day <sup>(1)</sup>. People with a learning disability should be able to expect the same quality of care as the general population. However, the standard of care provided is variable between hospital trusts throughout the United Kingdom (UK). This is occurring largely due to a lack of mandatory learning disability training amongst healthcare staff <sup>(2)</sup>; such training would allow healthcare staff to confidently make reasonable adjustments for patients with a learning disability so their individual needs can be met.

For my 'Teamwork and Leadership Activity' assignment where the aim was to explore a patient's journey through hospital, I chose to focus on a patient diagnosed with a mild learning disability and autism. This assignment has been an invaluable learning experience, allowing me to learn about healthcare inequalities experienced by patients with a learning disability and reasonable adjustments that can be made to support them. Throughout preparing this assignment, I have reflected on my other experiences of meeting individuals with a learning disability in a healthcare context.

## **Effective Communication and Positive Behavioural Support**

During my hospital placement, I have met Miss KB, a 31-year-old lady diagnosed with epilepsy, renal failure, mild learning disability and autism secondary to Tuberous Sclerosis Complex (TSC). Miss KB began treatment for depression following onset of suicidal ideation in 2018 and can occasionally present with challenging behaviour. (1) (3) (4)

Miss KB expressed that she often struggles to understand what healthcare professionals are explaining to her, particularly during ward rounds; this can lead her feeling anxious and unsure about what the next steps are in her care. Healthcare professionals are required by law to put reasonable adjustments in place when caring for patients with a learning disability, these can be as simple as using everyday language and avoiding jargon. (1) My experience of meeting Miss KB has led me to refresh my knowledge of communicating effectively with people with a learning disability, for example, limiting the number of key words in a sentence, avoiding jargon and idioms, using gestures and facial expressions and checking understanding (3,4).

Miss KB can sometimes display challenging behaviour, this has included being verbally aggressive towards staff in hospital. She felt the ability of staff to calm her down and respond to such situations was variable between staff members. Miss KB described one such situation where her preferred sanitary towels had run out and hence she was offered towels of a texture she was not able to tolerate. This lead to her becoming extremely distressed and verbally aggressive towards staff, declining to change her sanitary towel for a prolonged time period. Hearing this has given me an increased appreciation of the challenges which individuals with autism face due to sensory hypersensitivities. This discussion also prompted me to research what guidance is given to healthcare professionals regarding the management of challenging behaviour.

NHS England and the UK Government recommend that challenging behaviour should be managed in a way that that is in line with the principles of Positive Behavioural Support (PBS), in accordance with an individual's care plan, and in a way that only uses restrictive interventions as a last resort (5-8). The principles of PBS include understanding the likely causes and precipitants of challenging behaviour and using de-escalation and secondary prevention techniques to prevent crisis. When a restrictive intervention is used, this should be the least restrictive option required to meet that individual's needs at the time and should be used without deliberate application of pain and compromise of airway, breathing or circulation (9). Stopping overmedication of people with a learning disability, autism or both with psychotropic medicines (STOMP) is a national project lead by NHS England to prevent the overuse of psychotropic medications in people with learning disabilities and autism, minimising the adverse effects of their prolonged or inappropriate use. Strategies included in the STOMP healthcare pledge include exploring alternatives to medication, keeping individuals and their families or carers informed about their medication, reviewing and monitoring use of psychotropic medications inline with National Institute for Health and Care Excellence (NICE) guidance, and ensuring people feel able to speak up with concerns about inappropriate medication (7,8).

#### <u>Supporting Patients who are Unable to Communicate</u> <u>Verbally</u>

Whilst shadowing a doctor in the Emergency department (ED), I met a patient with a learning disability who was presenting with potential sepsis. He had visual loss and was unable to communicate verbally. The patient required a cannula in order to administer fluids and antibiotics; the doctor required three attempts to insert the cannula since the patient was strongly contracting his arms in pain. Both the patient and his mother supporting him became extremely distressed during the procedure. Following this experience, I have reflected on how patients with learning disability who are unable to communicate verbally can be best supported in hospital, particularly in terms of

minimising distress during procedures and physical examination.

On meeting this patient in ED, the doctor I was shadowing introduced himself to the patient in a calm tone of voice, knelt to be on the patient's level since he was in a wheelchair, and touched his hand. This was a great example of how healthcare professionals should communicate with someone with a learning disability who cannot communicate verbally. Tone of voice is an important component of communication, particularly if the patient is not able to fully comprehend the content of what you are saying and can help to put patients at ease. Kneeling is particularly important if the patient is in a wheelchair, since standing up can be imposing and make the patient feel intimidated. Physical touch can reassure patients, particularly if they have sensory loss. However, it should first be ascertained whether the patient has hypersensitivity to touch; this information could be found in an individual's hospital passport or by asking family members or carers. During cannulation, the patient's mother stayed to comfort the patient and an ED technician helped to stabilise the patient's arm. During procedures, it should be accommodated as far as possible for patients to have comforting items with them and to be reassured by family and carers throughout. During cannulation or phlebotomy, further methods can also be put in place, for example using anaesthetic cream and exploring atypical sites for venous access such as the foot where appropriate.

When caring for patients who are unable to communicate verbally, it is essential that healthcare professionals are aware of how they communicate that they are in distressed or in pain. Failure to interpret distress signs or disregarding concerns of family members and carers that an individual may be in pain can cause a patient to not receive appropriate analgesia or deteriorate medically; this could ultimately lead to morbidity or mortality. Information regarding an individual's communication needs and distress signs is likely to be included in an individual's hospital passport; it is also vital to work closely with family members and carers who can best interpret when an individual is in discomfort.

In this situation I was able to see the positive impact it has when healthcare professionals speak directly to patients with a learning disability regardless of their degree of learning disability, ensuring they feel listened to and included, opposed to only speaking to family members and carers. Furthermore, family members and carers can facilitate communication with the patient and provide a collateral history when necessary.

#### Self-care and Accessing Healthcare Appointments

Through caring for people who have autism and learning disability as a support worker, I have become aware of the challenges that can occur in self-care and accessing healthcare appointments for this patient group. I found supporting a lady with autism and touch hypersensitivity with personal care tasks such as washing and dressing, using the toilet, brushing teeth and applying creams was challenging at times. This

increased my awareness that touch hypersensitivity could potentially increase an individual's risk of moisture lesions, cutaneous and urinary tract infections, and dental decay. When accompanying her to an appointment with a special care dentist, she became distressed and anxious when the dentist inspected her teeth, only opening her mouth for a couple of seconds. This increased my appreciation of the challenges of physical examination of patients with autism and sensory hypersensitivity, particularly by healthcare professionals who have not had learning disability training (2).

In this role, I also accompanied a lady with learning disability who experiences periods of elated mood, overactivity and agitation to a number of outpatient clinic appointments. From this experience, I can appreciate how simple reasonable adjustments such as offering a quiet room to wait in and offering appointments at a quieter time of day can have a profound impact. Had I known that I could have requested this for the resident I was caring for, I feel that she would have been calmer and more settled when attending clinic appointments. When discussing reasonable adjustments that can be made for patients with autism, my General Practice tutor explained how allowing patients to wait outside the surgery or in a quiet room can enable patients with autism to come into the surgery for appointments instead of being seen at home.

Moreover, I have become aware of the barriers which may inhibit people with learning disability from maintaining a healthy lifestyle. For example, not being able to go out unaccompanied, being unable to access opportunities to exercise such as gym classes due to lack of understanding and appropriate support, and coping with complex physical co-morbidities such as cerebral palsy. It may also be more challenging for individuals with a learning disability to maintain a balanced diet due to having less understanding about different food groups and portion size. Attending a weekly fitness club for people with learning disability where members played active games and learnt about aspects of healthy eating, such as the sugar content of different types of cereals, raised my awareness of the importance of charities such as Brandon Trust and Mencap in facilitating opportunities for people with a learning disability to exercise.

#### **Mental Illness**

Meeting patients in hospital with a learning disability who have co-morbid mental illness has increased my awareness of the profound impact that mental illness can have on individuals with a learning disability. Even mild mental illnesses can have a severe impact on the individual's ability to carry on with their day to day activities and can impinge on quality of life <sup>(10,11)</sup>. Such people may sometimes decline support with personal care, food and fluids as well as becoming physically and verbally aggressive towards staff and other residents during periods of low mood and anxiety. As a support worker, I encouraged people with learning disability to maintain their nutrition and personal hygiene during these periods and supported them to



express difficult feelings and thoughts whilst providing emotional support. Individuals with a learning disability may also be less able to articulate and express how they are feeling and may present with mental illness in a non-specific way, for example, declining food, insomnia and becoming withdrawn or aggressive <sup>(12)</sup>. This presented a challenge when working as a support worker since it was occasionally unclear whether changes in behaviour were due to an underlying physical cause, for example constipation or abdominal pain, or were due to symptoms of their underlying mental illness; however, I found my ability to interpret a resident's body language, facial expressions, vocalisations and behaviour changes improved as I got to know the residents over time.

Conclusion

In conclusion, my experiences of meeting people with learning disability during my hospital placement and as a support worker has increased my awareness of the inequalities in healthcare received by individuals with learning disability. Reasonable adjustments made for such people and adapting communication to suit the needs of such individuals can have an immense impact on them and their family members. I will act as an advocate for individuals with a learning disability, working to ensure that they receive good quality healthcare whilst continuing to develop my own skills in communicating with individuals with learning disabilities and making reasonable adjustments.

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## Conference watch







# Neurodevelopmental Psychiatry Day Event 2020



Dr. Mariam Omokanye

ST6 Psychiatry of Intellectual Disability

Nottingham

Following the success of the previous two East Midlands Neurodevelopmental Psychiatry Study Days in June 2018 and June 2019, plans began in late 2019 to hold the third annual conference the following year. Plans were repeatedly postponed due to the arrival of COVID-19 and it soon became apparent that there was a need to consider alternative ways of holding the conference. We decided that, with the use of the Microsoft Teams platform, the conference was able to proceed remotely. Attendees were mainly medical students although some core and GP trainees also joined. As part of the adaptations to the remote offering, biographies of the presenters were sent to delegates prior to the event and feedback was obtained, remotely, using an online feedback questionnaire.

#### **Aims**

As per the 2018 and 2019 Conferences, the organisation of the event was a joint effort between Consultants and Higher trainees in Intellectual and Developmental Disabilities (IDD) as well as Core trainees working in the speciality from Nottinghamshire Healthcare Trust and Leicestershire Partnership NHS Trust. The project was, this time, led by Dr Samuel Tromans (ST6); supported by Dr Mary Barrett (Consultant/TPD) and Dr Niraj Singh (Consultant/ES). Valuable contributions were also sought from Dr Rebecca Brown (ST4), Dr Prabhleen Jaggi (MTI trainee), Dr Mariam Omokanye (ST6), Dr Keir Jones (ST5) and Dr Kate Livings (CT1).

The aim of the conference was to offer medical students and junior doctors insights into the speciality as well as educating attendees on relevant clinical topics. The drive for the event was an acknowledgement of the interface between lack of opportunities to experience the specialty (both clinically and academically) and declining recruitment rates. It was also important to offer attendees an experience that could enrich their understanding of topics relevant to the speciality irrespective of whether they progressed into a career in IDD or decided to pursue other specialties.

#### The Event

The event was attended by approximately 84 delegates, an increase of over 200% from the 2019 conference. The need to estimate the total attendance is born from some delegates joining at different intervals (e.g. due to clinical commitments). Whilst not available in time for the conference, the MS Teams platform now has a function whereby meeting attendees are automatically recorded. Delegates joined the meeting, for the most part, from the East Midlands although the organisers were pleased to welcome attendees from further afield (including Leeds, Glasgow, London, Bristol, Norwich, Lancaster, Birmingham, Manchester, Warwick, Newcastle, Cardiff, Aberdeen, New Jersey, Canada Bulgaria, Belfast, The Philippines, Malaysia, Tehran and India!)

The Chairs for the event were Dr Ken Courtenay (Chair of the Royal College of Psychiatrists Faculty of Intellectual Disability Psychiatry and Consultant Psychiatrist in Intellectual Disability), Dr Sam Tromans (ST6) and Dr Keir Jones (ST5) with the closing address being delivered by Dr Niraj Singh (Consultant Psychiatrist). Topics from the day included "Mental Health and Challenging Behaviour" (Dr Peter Cutajar – Consultant Psychiatrist), "Autism" (Dr Mary Barrett - Consultant Psychiatrist), "Attention Deficit Hyperactivity Disorder" (Dr Raj Bhaker – Consultant Psychiatrist), "Intellectual Disability Research" (Prof Regi Alexander – Honorary Professor and Consultant Psychiatrist in Intellectual Disability and Dr Sam Tromans – Honorary Academic Clinical Lecturer and ST6 in Intellectual

Disability Psychiatry) and "Physical Health Needs of People with Intellectual and Neurodevelopmental Disabilities" (Dr Shweta Gangavati – Consultant Psychiatrist and Dr Sam Pollen – Core Psychiatry Trainee). The event concluded with a Discussion Panel, giving attendees the opportunity to ask questions about a career working with people with Intellectual and Neurodevelopmental Disabilities to a panel of Consultants and Higher trainees ( Dr Rebecca Brown- ST4 and Dr Mariam Omokanye – ST6 as well as Dr Niraj Singh, Dr Richard Welfare and Dr Ken Courtenay)

#### **Feedback**

Feedback from the attendees was incredibly positive, with consistently high scores awarded for the quality of the visual materials, the enthusiasm and communication skills of the presenters, timekeeping and the structure of the event. The consensus from the delegates was that the interactivity of the day could have been improved, with some suggestions such as using online polling apps and quizzes. Many of the delegates wished to preserve the online element of the conference in future years. Comments from the day included:

"I really really enjoyed this conference and feel like I've come away learning a lot and hungry to learn more."

"Inspiring and insightful event, definitely made me think about a career in this field."

"A great day all round-thank you very much. As a medical student, it was very helpful to hear about the various career routes speakers had taken into ID psychiatry.

Hearing from so many passionate doctors who loved their jobs really attracted me to this career!"

"It was a great opportunity to learn about a specialty I hadn't previously encountered."

"Really inspiring, I attended as I have very little experience of patients with intellectual disabilities and will be applying for a post in core training! Stumbled across the event via Twitter! Thanks so much"

"Thank you very much for offering your time and effort for this great event. ID has been a largely hidden subspecialty from me and in considering CAMHS as a career path I have discovered how much about what I love about psychiatry and development can be found in ID. The structure was excellent and one of my favourite Teams online conferences with very well chosen break lengths and periods, and a range of guests from clinical and academic

backgrounds giving different flavours of career options available."

"Really useful presentations and catered to all abilitiesthank you! It was very nice to gain more exposure on topics which are only briefly covered at an undergraduate level. Thank you!"

"Please have more online conferences, will really help students from across the globe .The whole event was wonderfully organised"

"A wide range of information was covered which was great. It was pleasant to see the great importance placed on the holistic treatment of the individual with LD, and the respect paid to the individuals in question. A point that stuck with me was that as practitioners, we will be advocating on behalf of the patient and it is our responsibility to make sure no physical issues get missed. The importance of not missing physical issues due to communication barriers was well emphasised, and definitely something I will carry with me on placements."

#### **Essay Prize**

A new addition to the Neurodevelopmental conference this year was the introduction of an Essay Prize, entitled the Professor Sab Bhaumik Essay Prize, in memory of the late Professor Bhaumik. Delegates were invited to submit essay's entitled "How can we improve the physical health of people with an intellectual disability?" with the winning essay receiving a £200 Amazon e-voucher. Essays were judged on originality, clarity, creativity and evidence base. The judges took great pleasure in reading all entries, appreciating the time and effort that had been spent by the delegates. The winning entry was announced, on October 14<sup>th</sup> 2020, as the essay by Gemma Swann (University of Glasgow, pictured below). The essay was deemed as excellent by the Judges, with one commenting that it was a very thorough and holistic approach to answering the question.





## **Arts Review**







# **Experience: Amici Dance Theatre Company**

**Gurpreet Dosanjh** 

**Dance Movement Psychotherapist** 

Founder and Teacher at Brixton Yoga, South London

My name is Gurpreet Dosanjh; I've been a company member with Amici Dance Theatre for over 12 years performing nationally and internationally with them - with no prior dance training...gulp!



Prior to that, I worked for 5 years in Parliament for a high profile MP. Why am I talking about myself so much? I'm not really sure...I guess I am still trying to come to terms with how I went from the inner circle of a political office to the magical circle of Amici Dance Theatre.

I feel like I can talk about how important an integrated company like Amici has been for me, I'm not sure I can comment on the effect it has on those diagnosed with an intellectual disability. I personally feel like some people with ID have a much more acute, sensitive and confident relationship with their body and the ability to move spontaneously - with authenticity. They are the key players who make Amici special, as opposed to them benefitting from Amici or an arts space. Rather than the arts being a holding space for them to develop their artistic ability, it is their artistic ability that creates the holding space. In this frame of reference, it seems less like an intellectual *disability* but an intellectual *ability*: derived from the close connection that some people have with their body and therefore, the ability to demonstrate this to the wider world in a performance piece.

I'll start from the very beginning and hope that somewhere in this story you can see what Amici is all about and what role arts can play for those diagnosed with an intellectual disability.

In 2006 I was sat on a park bench gutted that I was overlooked for a promotion and started reading through the Guardian Job vacancies. I stumbled across an advert for volunteers to befriend a young person with ID who had difficulty making friends and socialising. My cousin in the Punjab, India, has Down Syndrome and over numerous trips to India since a child, we became close. I felt compelled to support this charity and stop feeling sorry for myself (in retrospect, I was never built for politics anyways); I met this young fella and we became instant friends.

Over time I learned that he was a member of Amici Dance Theatre. I went to see their show on the main stage of the 'Lyric' in Hammersmith - a sell-out show in a 550 seat venue. I was blown away by what I saw. This wasn't about giving people with ID a platform to perform - this was a search for an authentic human experience that could be conveyed on stage in movement and didn't really have a lot to do with the diagnosed disability. Amici's shows are a vehicle for the expression of the innermost feelings that we all have. It was a way to connect everyone together outside of the preconceived, largely socially constructed, barriers. Yup, I know I am going on here - but - you have to see a show to know what I mean.

A few weeks later I was asked by my friend's mum if I wanted to take him to his Amici rehearsal: it was a resounding 'yes' from me. As I walked into the rehearsal space, star-struck by the actors who I had seen on stage a few weeks ago, the charismatic and utterly charming director, Wolfgang Stange, welcomed me in as if I was an old friend! I felt immediately relaxed. And that was the Amici way - a totally relaxed and welcoming environment where everybody belonged regardless of their dance ability, knowledge or training!

And then the company was working through improvised movement in three groups of four. The last group only had three people in it. Wolfgang looked around the room and then at me watching on from the side-lines and said 'well...are you in or are you out?', pointing to the group with one person missing.

Prior to this my experience of dance was largely in a nightclub or on the dance floor at a wedding finding the kind of shapes that such an environment will allow. In that moment, as a trickle of sweat rolled inelegantly down my spine, I was supposed to say, 'thank you for the kind invite sir, but I am fine'...however, as I started to speak, I found myself standing up and joining in. When it was our turn for improvised movement to a random song, I was frozen stiff. I couldn't move and felt incredibly embarrassed and self-conscious. Carol, who has been diagnosed with Down Syndrome and doesn't communicate more than a couple of words verbally immediately knew what to do: she came in and reached for my hand and calmly said 'follow me'...and I felt an incredible sense of relief. I felt supported and held by her and then progressed to some kind of shamanic movement based outpouring. It was a pretty amazing few minutes.

Wolfgang said at the end - 'Well...(he started a lot of sentences with 'well') they seem to like you - want to come back?' I was hooked and went every week!

Each week a different person would come to me and share something about the way they move and slowly but surely I learned more and more. Every week I learned to be more confident with my body and increasingly became less concerned with how I looked in movement, and more and



more concerned with how I felt. I get the impression that many of the dancers at Amici have an incredible feeling of joy fill their bodies and then they move with this feeling. They are not afraid to channel and explore the darker emotions too. I know this, because I feel the same. I have learned so much.

Amici is world famous as an inclusive dance theatre company integrating able-bodied and disabled artists and performers. Founded by Wolfgang Stange in 1980, its productions and workshops have had a major impact world-wide, challenging conventional attitudes about disability and the arts. Amici is open to all; it is not a space that gives people with ID support, but rather a safe, creative space that is created *by* the dancers with ID.

Over the lockdown I have been fortunate to help make the move to a weekly online class, taking the lead on some weeks. I've performed nationally and internationally with the company and never in my wildest dreams would I have thought that any of this would happen. Last year in collaboration with Rosie Leak (an ID choreographer, poet and performer) and Elaine Thomas (dancer and senior dance lecturer at Roehampton University) we choreographed our very own 45 minute dance piece and performed it at the Skibbereen Arts Festival in West Cork, with a live quintet playing the soundtrack. At every single juncture Rosie came up with an idea that pushed the choreography to completion. Her ideas were outstanding, real and beautiful.

My work at Amici, helped ignite an interest in movement and the body and eventually led me to training as a Dance Movement Psychotherapist (DMP). My psychotherapy work was clearly influenced by my experiences at Amici - what I could notice, empathise with and hold onto for my clients was different because of what I had learned. My DMP training combined with my theatre work has also helped me to run a Yoga studio. I try to nurture an inclusive and cohesive group identity. I try to welcome people into my class as I was welcomed at Amici and I sometimes think of the group I am faced with in a class as a person. I consider what type of person is present in the room and what sort of instructions, humour and support does this person need in my interventions – and I adapt the sequences accordingly.

This is an essential and honest account of what Amici means to me; I'm not entirely sure what else I can say about the company, but I am pretty sure that everyone at Amici, regardless of their diagnosed condition, feels exactly the same way and has had the same journey. Amici is now offering regular open workshops for people to come and witness their method - I highly recommend it. And because they are legends and want to help people over lockdown - it is all donation based! I run a regular yoga and dance fusion class for the charity that originally introduced me to Amici - it's funny how things go sometimes. I could write another whole article about those sessions and what happens there!

For now, thanks for the chance to share my thoughts and I hope you get the chance to see one of our shows in real life soon.



# DO YOU WANT TO MAKE HISTORY?



# RCPSYCH'S FUTURE ARCHIVES COMPETITION

We want YOU to tell future generations what psychiatry was like in 2020-2021. Everyone is invited to participate.

You can submit prose, poetry, drama, film, or even a comic strip - anything up-to 1000 words. All submissions will be archived permanently at RCPsych.

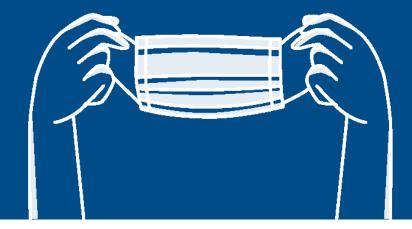
Winners will receive an iPad and will be invited to talk at the RCPsych International Congress.

www.rcpsych.ac.uk/futurearchive

Contact: archives@rcpsych.ac.uk

Closing date: 30 April 2021





# Upcoming conferences

<u>DATE</u> <u>TITLE</u> <u>LOCATION</u> <u>ORGANISATION</u>

#### **MEETINGS**

All face-to-face conferences and events associated with the RCPsych have been cancelled for this year (2020), details for 2021 not yet finalised; please see the College website for the most up to date information regarding online/virtual seminar details.

Please see <a href="https://www.rcpsych.ac.uk/events/conferences">https://www.rcpsych.ac.uk/events/conferences</a> for most up to date details



# COVID-19 Resources

The RCPsych ID Faculty has also provided a number of resources to support professionals and patients during this pandemic.

These can be found at: <a href="https://www.rcpsych.ac.uk/members/your-faculties/">https://www.rcpsych.ac.uk/members/your-faculties/</a> intellectual-disability-psychiatry/news-and-resources

These include a statement from the Faculty about the current situation as well as a number of other resources.

# Upcoming prizes, awards and bursaries

<u>DATE</u>	TITLE	LOCATION	ELIGIBILITY	PRIZE
PRIZES				
30.04.2021	The Brian Oliver  Medical Student  poster prize	Submission by email then winners will be invited to present a report at the annual residential meeting.	CT1-ST6 in UK approved training scheme or within 3 years of consultant post	Prize: £500  Awarded for research (original work or literature review) undertaken in Psychiatry of Intellectual Disability
26.08.2021	The Jack Piachaud  Medical Student  poster prize	Presented at the Faculty Autumn meeting, usually held in September each year (await details of 2021 conference arrangements).	Medical students based at a UK university	Prize: £75  Students should present a poster based on a project/audit in learning disabilities at the our Autumn residential conference.
26.08.2021	The Alec Shapiro Prizes for Specialty Trainees	Presented at the Faculty Autumn meeting, usually held in September each year (await details of 2021 conference arrangements).	UK specialty trainee CT/FTSTA 1-3, ST4-6/ LATs and SpR, or be a member of the College in a training post	Two prizes, best poster presentation (£150) and best oral presentation about a topic relevant to Psychiatry of ID (£200).
31.12.2021	The Gregory O'Brien travelling fellowship	Submit application proposal by email; if successful you will be expected to submit a report and present at one of the Faculty meetings	CT1-ST6 in UK approved training scheme or within 3 years of consultant post	Prize: £1000  Awarded every 2 years, to encourage psychiatric trainees to broaden their academic and clinical knowledge in a centre of excellence (UK or abroad)
31.05.2021	Bursary for psychiatrists from LAMI countries	For attendance at the annual residential meeting and delivery of workshop, oral or poster presentation.	Psychiatrists living and working in LAMI countries (Bands C and D, according to World Bank Definition)	Award: up to £1500 to cover economy class travel to and accommodation during the meeting.
Available throughout the year	Faculty of Intellectual Disability Psychiatry bursary	Application by email	Doctors in training, Staff grade or associate specialists	Up to £200 per applicant having difficulty securing funding elsewhere, to attend any appropriate educational event

