Learning Disability Professional Senate

MINUTES

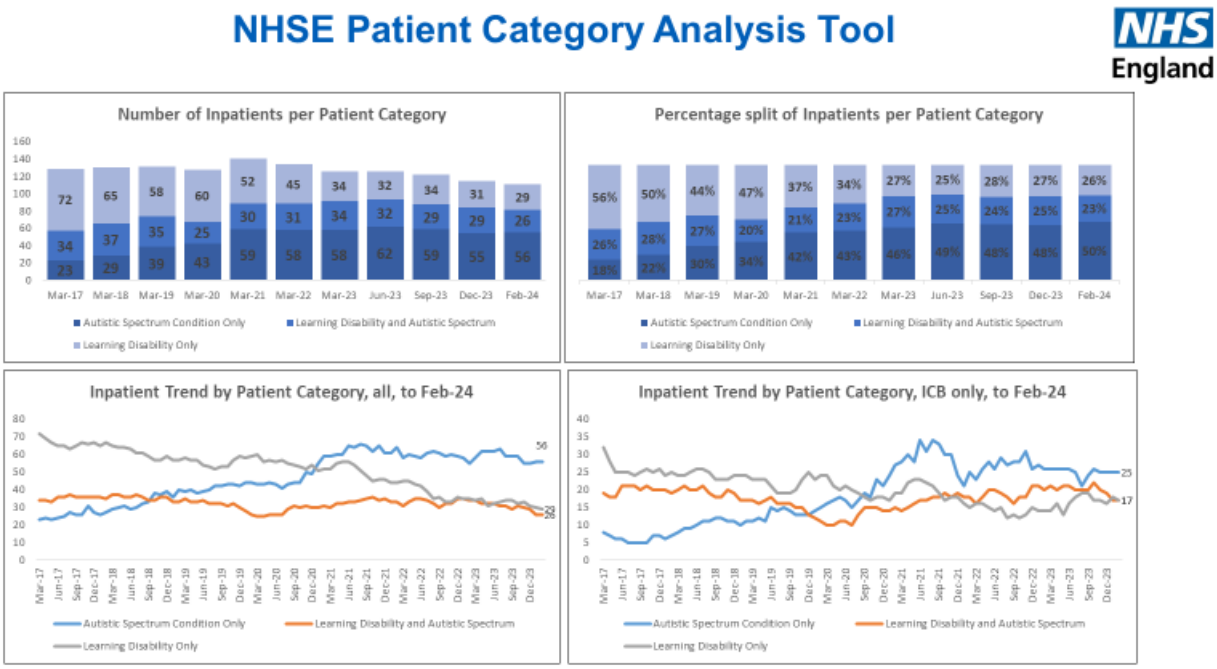
Learning Disability Professional Senate
Meeting held on Monday 3rd June 2024
09:00am to 12:30pm via MS Team

1.	**Welcome, Introductions and Apologies**
	Dr Roy welcomed all to the meeting and introductions were made **Present:** Ashok Roy Sandy Bering David Gerrard Vivian Cooper Briony Caffrey Marie Lovell Alex Clark – on behalf of Martha Laxton-Kane Joanna Dwyer Isla McGlade Leanne Gelder Lynette Kennedy Megan Bowes Robert Ferris Sarah Swindells Siobhan Rogan David Standley Susan Hastewell Wendy Ruck Heather Hanna Jason Crabtree Jonathan Campion Debbie Kenny (Minutes) **Apologies**: Vicki Baker Martha Laxton-Kane Wendy Ruck Charlotte Annesley Sunpreet Kandola, Vicky Romilly Kirsten Lamb Ruth Wynn Jones

	Kathy Peterson Samantha Harker David Nuttall Indermeet Sawhney Katherine Peterson Carl Shaw Ken Courtney
2.	**Minutes of the last Meeting**
	The minutes of last meeting were agreed as a true record of events. LD Professional Senate Minutes 4 Mar
3.	**Action Log**
	The Senate action plan was shared and updated – (see below) LD Professional Senate action tracker **Senate Conference** Prof Roy reported the Senate Conference scheduled to take place on 7th May was stood down and has now been rescheduled as an online event on the 17th of October 2024. **Action Debbie will send out a meeting invite to hold the date in your diaries.** **Obesity Statement – Briony Caffrey** Briony advised she is planning to meet with Ashok and Vicki in the coming week to get some clarity on the content and that she is optimistic she will have something more substantial to bring to the September Senate meeting. **Handover between Services – Lynette Kennedy** Lynette confirmed she is meeting with NHS England around this. NHS England are doing a piece of work on this and Gemma Sharp is leading it. **Action Lynette is meeting with her next and will report back to the Senate Meeting in September.** She also raised that the Senate was going to produce a statement about joining together people with LD and Autism and asked whether it available. Prof Roy confirmed that Martha is leading on this and had produced a presentation at the December Meeting. Vivien asked whether this is available on the website as there is concern that the system has grouped these people together and it's a hugely diverse population and it would be helpful to have something from the Senate giving a view on it. **Action Prof Roy advised he will get in touch with Martha and will ask her to add it to the website.** Sandy Bering advised that this data is now being split by people with LD/people with LD and Autism/and people with Autism only. He advised that this data is being looked at to track the changes since the Programme started.

Robert Ferris reported from an inpatient bed perspective we are looking at 3 distinct groups and the Senate needs to define what they will focus on.

Sandy Bering shared the Patient Category Analysis Tool



Sandy reported there has always an issue around Autism and Learning Disabilities and an overlap. The debate for the Senate is there a completely distinct group working around Autism? There is an issue around joint working and a lack of clarity around our policy and how we support people with Autism.

Prof Roy mentioned that when the Senate was asked whether it should take into our remit Autistic populations and their services, the feeling then was that we should stick to our original remit of concerning ourselves with Learning Disability Services, whether people had Autism or not, but within the Learning Disability population. In other discussions when Autistic people were asked about services there was a reluctance to have anything to do with Learning Disability Services. There has been talk about an Autism Senate however this has not happened to date and there is no counterpart multi-professional group of people working in Autism only services across the UK at present.

Vivien raised that there is an Autism Act, Autism Strategy and Autism Programme Board but there is no equivalent for people with Learning Disabilities and felt this should be an agenda item for the next meeting for further discussion.
Action: Agenda Item for next meeting

Jason Crabtree felt there is a risk of some of the interventions that we use for people with intellectual disabilities being challenged or questioned if people with Intellectual Disabilities and Autism are combined.
Prof Roy felt it is difficult as in most places the people who deal with Autism Services, whether they are providing them or commissioning them are by and large the same as the people doing it for Learning Disability.

Siobhan Rogan shared that in Northern Ireland there are a large number of Autism specific services which have largely been developed to the exclusion of people with a Learning Disability and people with a Learning Disability and Autism have become excluded from those services and from that voice. This is having a negative impact on people with Learning Disability and Autism and she would welcome a discussion around how we get the needs of people with Learning Disability and Autism included in the discussion to ensure they are not forgotten about.

Ashok thanked Siobhan for raising this very important point and stated that he is interested to hear about the unintended consequences of this and agreed with Vivien that this topic should be revisited at the next meeting but we would need the views of David Nuttall who is not present today. He also agreed to add the document Martha had also presented at a previous meeting and ensure that it covers all the points made today and is available on the Website. **Action Ashok to share Martha's document for update**

Vivien raised there used to be a Learning Disability Observatory which provided data for people with Learning Disabilities and asked whether we have this data?. Briony Caffrey replied from recollection it was the Joint Strategic Needs Assessment that was putting that into local areas rather than a national one. AR raised the problem we currently have is the only data we have is from Transforming Care which is almost all confined to inpatient care and asked whether Robert had any data. Robert replied that only data sets they have are assuring transformation and material from LeDeR.

Claire Swithenbank reported that the former NHS Digital publish a generic health and care data which looks at a more and shared the link below.

https://digital.nhs.uk/data-and-information/publications/statistical/health-and-care-of-people-with-learning-disabilities

Dave Gerrard confirmed the data is owned by NHS England (previously NHS Digital). This data set only pulls from 56% of GP databases and felt it is useless having a data unless it has 100% coverage.

Lucy Legiewicz-Preston shared that they have been doing some work on workforce modelling around how to grow, retain, sustain attract people in both Learning Disability and Autism spaces and what that mean in terms of where we are now and what is required for the future.

Alex Clark shared that in In terms of psychological professions, Jason and a BPS CYP-ID colleague Louise Aker have recently completed the paper on workforce issues:

Expanding and developing the workforce to serve autistic people and people with intellectual disability | BPS - British Psychological Society

Marie Lovell shared the links below. She advised they have two funding sources open for training for individual employers and their PAs and both funds can be accessed by people using social care direct payments, their own money and/or personal health budgets.

https://www.skillsforcare.org.uk/Funding/User-Led-Funding/User-Led-Organisation-Funding.aspx

https://www.skillsforcare.org.uk/Funding/Individual-Employer-Funding/Individual-Employer-Funding.aspx

Briony shared the links below

From the British Dietetic Association, Learning Disabilities Committee. A one day course on capacity assessments and diet, weight and health is live since January. https://www.bda.uk.com/practice-and-education/education/cpd/bda-classroom-courses/completing-capacity-assessments-for-health-risks.html

Contributions to Obesity Health Alliance and Caroline Walker Trust will be published later in the year. The Nuffield Trust Research Report referenced some work from the BDA LD committee in its latest LD report

https://www.nuffieldtrust.org.uk/sites/default/files/2024-03/Nuffield%20Trust%20-%20Learning%20disability_WEB_FINAL_1.pdf

4.	**National Updates (9.30 -10.30**

Department of Health – David Nuttall – Apologies received

Scotland - Isla McGlade

Consultation update (see newsletter below)

LDAN Bill newsletter May 2024.docx

Isla updated the Learning Disabilities Autism and Neurodivergence Bill has been out for consultation since the end of December 2023 and closed at the end of April 2024. There were over 900 responses from a variety of groups and individuals. All responses have been analysed by an Independent company and a report will made available in the coming months. This will help to inform the work going forward. As part of the process, there will be panel meetings with people with lived in experience (LEAPS) and stakeholder panels. There are also numerous events happening across Scotland in relation to the consultation which will inform policies going forward.

Northern Ireland - Siobhan Rogers/Heather Hanna

Learning Disability Strategic Action Plan
The Department of Health in Northern Ireland are overseeing the LD Strategic Action Plan to propose a future model for people with a Learning Disability across Northern Ireland. This is expected to go out to Public Consultation over the summer and will focus on keys areas such life changes, health and wellbeing, carers and families, meaningful lives and citizenship, home, mental health and behaviours of concern. The Northern Ireland Health Committee had a session two weeks ago on Learning Disability and are extremely interested in this. The challenge will be around the differences in relation to the meeting the mental health and behavioural needs of people with a Learning Disability and in particular the role of inpatient care. Siobhan raised that this item should have been an agenda for todays meeting as it felt

there may be a role for the Senate to help to define it. Ashok asked Siobhan to expand on this today rather than delay it.

Siobhan explained Muckamore Abbey Hospital due to close in June 2024 provided services for 3 out of 5 of their Health and Social Care Trusts and for 5 out of 5 are ICU and Forensic inpatient services. The 2 other Trusts had a small inpatient unit each. The Minister has now made an announcement that Muckamore will be closing. This is an opportunity to design how many specialist inpatient they need for people with a learning disability and all components around the service. The problem they are facing is that gathering information for people with learning disability is difficult. Furthermore it feels like there is an acceptance in the system that there are no community placements and it is okay for people to remain in hospital. The reality is they are coming to harm and raised that this needs to be highlighted to decision makers to help inform the development of more appropriate evidence based services to meet need. She shared that her view around admission is it should be planned after assessment and treatment options have been exhausted in the community and in the shortest possible time and should never happen in response to a social care crisis. The other question is what does an ideal admission look like in terms of duration? It is about as a senate coming up with a position on this so that people can start to think about coming up with a standard.
Ashok stated that we are dealing with figures that suggest a certain number of beds for certain populations. This was formed on the basis of a longer term strategy through Transforming Care a number of years ago. We also have a similar situation in some parts of the country where there are no inpatient beds and people are struggling with the same issues that that Siobhan is struggling with because they have to create new services.

Robert stated that people occupying beds are predominantly doing so due insufficient community based services and that beds should not be looked at in isolation of what needs to be what needs to be true in a community based setting for that to function. Jonathan agreed with Ashok that from an England perspective there are much bigger issues than just a single ICB and a knitting together of the bed strategy plans from an England perspective across ICBs is going to be critical otherwise there will be proposals for non-sustainable services put forward that will not be of the right quality or configuration.

Claire reported that Lancashire and South Cumbria do not have access to any Learning Disability beds. They are in the process of building 14 beds. Part of their challenge is around flow and clarity regarding discharge planning from the point of admission. For example is the admission planned, does it have a clear outcome and does it acknowledge beds should not be used as place for safety? If there is no community provision or if and it is going to take time to commission what can be done in the interim and within the National Transformation Plan in England how do we take those steps over the next three years to know that people are not being admitted to hospital as a place of safety when community packages fail.

Ashok highlighted the issues are going to be identical regardless of different legal frameworks and jurisdictions and recommended Siobhan and Claire meet to discuss this outside this meeting to get a more in-depth analysis.

Sandy Bering echoed the conversation above that in mental health they are having the same issues. In central Manchester 37% to 40% of the beds are occupied by people clinically ready for discharge who are not moving on. He raised concern around the increasing number of people coming in who are struggling and families who are unable to do anything and we are opening up whole wards or closing whole PICU units for individuals and felt that we are not being honest about people not being supported.

Heather felt it is less about numbers and more about what the role is in the wider system, in the context of the other services. There is a clear role for mental health but it is about defining that in the context of specialist LD services.

Siobhan raised that it is not only about what a quality service looks like and there needs to be some clarity around what the role of inpatient care is.

Siobhan stated that we continually talk about what it is not for and the question is what is it for? Ashok stated that those working across inpatient and community settings find there is no universal answer and a lot depends on what is happening around the person and how people decide to manage risk and in the end it will come down to whether the risk is manageable in the community or does it need to take place in an inpatient setting and this often has to do with lawful control of risk, violent behaviour, self-destructive or self-induced behaviour. He shared there is no clear line and raised that has found two cases being managed quite differently depending on the risk sharing appetite of community services and how well they feel supported in managing those risks. Nobody wants is to be bit to be left with a problem on their own and to a point the hospital provides this as a default setting for most people. The reason why people are stuck for months and years is because nobody is willing to share the risk of that person through other agencies and stressed the discussion must take place in an interagency context where the bed is seen as a precious and expensive resource. The question is how do we stimulate the development of high quality community providers, as this is the limiting factor in the equation. He shared his experience is that we find a good provider and patients are heaped upon them until the placement breaks down and they go back to hospital.

Madelaine Cooper agreed with Ashok around risk and multi-agency sharing. She mentioned that at the Challenging Behaviour Foundation event last week someone spoke about a person having 10:1 staffing in an inpatient setting and even if the risk appetite is they can be discharged to a community setting or their own home with 5:1 if the money is not moving with them or if they are on a S117 social care will be unable to afford it. Ashok raised there is nothing special about the patient characteristics. There is no behaviour violent, destructive or challenging enough that it cannot be overcome by risk sharing. The only way you can reduce the staffing is by building a trusting framework around multi agency input.

Ashok suggested Siobhan to give some thought around developing a plan for the Senate to support Northern Ireland as a professional group.
Action: Siobhan to consider developing a plan for the Senate

Wales – Dr Ruth Wyn William – Apologies sent

England – Ken Courtney
Ken Courtney sent apologies and provided feedback below.

Children's Services
NHSE is developing a model of care for children's mental health services that will include provision for CYP-LD. It seeks to achieve greater integration of services that will also apply to children with learning disability and to autistic children. Once it has been developed internally, it will go to external consultation to include members of the Senate.

Digital RADF
The Health Improvement Team launched the reasonable adjustment digital flag (RADF) in acute sector and mental health services. It is an important innovation in services that will highlight to health staff where they need to make reasonable adjustment to support people. It should help services fulfil their duties on equity of access to services.

Neurodevelopmental Disorders Credential
NHSE is working with the Royal College of Psychiatrists in developing the credential on NDDs for psychiatrists. Ashok will have more information on it.

NHSE Stakeholder Webinar
The planned webinar has had to be postponed until after the general election. We plan to hold the next one in July 2024.

Visits to Services
In my role as National Clinical Director, it is important for me to connect colleagues in services. So far, I have had the opportunities to visit children's in-patient services and offender services. I have met colleagues in CANDDID in Cheshire in March and with the CBF-NSG in May 2024. I am happy for colleagues to contact me regarding services that are providing novel or innovative care to people. On account of the current general election campaigns, I am restricted in such engagement until after the election has taken place.

Questions
Jason Crabtree queried multidisciplinary input into the neurodevelopmental credential in terms of other professional groups.
Ashok replied that it is being developed by Royal College of Psychiatrists and is therefore likely to be developed for doctors. It may in future be accessible to other professionals.

Ashok asked whether Vivien had Did you have any thoughts or reflections following the meeting she had recently on the National Strategy Group

Vivien Cooper shared there were over 20 initiatives. They will be completing a write up around the day and will share the posters (see link below)
Co-Producing a Lifelong Action Plan (challengingbehaviour.org.uk)

5.	**Rolling Items (10.30 -11.30)**

STOMP – Dave Gerrard

Dave Gerrard gave apologies on behalf of Carl Shaw.

Dave Gerrard reported that Carl is currently going through all of the 660 responses and is pulling out a number of key themes and once the themes are clearly identified he will arrange an event online or in person. He explained there has been a range of responses from people with a Learning Disability, People with a Learning Disability who are Autistic, and people who are Autistic and it would be good to not only understand themes within the groups, but also to understand the wider themes and how we can incorporate those into the response hopefully by the end of the summer.

There are still ongoing discussions around the standards of STOMP and STAMP. He has met with Ashok to discuss what they may look like in practice and some of the themes we need to consider within that work. There are also ongoing discussions with the Royal College of Psychiatry Faculty and he will be meeting with Rohit later in the week to discuss the College response.

Regarding the MindEd modules. There are currently 6 STOMP based modules. Some are open to people with lived experience and some are targeted more at health and social care professionals to understand about psychotropic prescribing and what to do around challenging psychotropic prescribing if it's felt to be no longer beneficial or to prevent prescribing by considering other ways of helping people. This has been going on for approximately 2 years and they have now hit 25,000 enrolments but because of the upcoming election they have had to delay the launch of the next modules 7-10 which is aimed at a more specialist audience and goes into defining the element of discussion around considering challenges to medication and what that looks like in practice and includes an emphasis on the potential pitfalls. There is no date at present for the next launch but based on the popularity of the first six modules they are hoping for similar response.

Marie Lovell asked wither this work has any links with the project below (see link) which was going to launch a video but also may have been paused due to the election

https://raceequalityfoundation.org.uk/projects/annual-health-checks-for-people-with-a-learning-disability/

Dave Gerrard shared the following link

https://www.england.nhs.uk/publication/stomp-stopping-the-over-medication-of-people-with-a-learning-disability-autism-or-both-translations/

Multicultural STOMP - Hassan Mahmood

Ashok Introduced Hassan Mahmood as the new CMO for Coventry and Warwickshire PT.

Hassan shared his presentation below and shared the background around Multicultural STOMP, innovation and next steps.

Multicultural STOMP Presentation.ppt

Dave Gerrard share the following link
https://www.nhsrho.org/research/review-into-factors-that-contribute-towards-inequalities-in-health-outcomes-faced-by-those-with-a-learning-disability-from-a-minority-ethnic-community/

Jason Crabtree thank Hassan for his presentation and raising awareness and aware of some of the challenges of those from more diverse backgrounds.

Vanessa Bibb asked to share a webinar autism, ld if meds are going to be reduced. …. Within certain communities if you are interacting with elders you look away which is part of culture and not necessarilty autism.

Dave Gerrard thank Hassan for his great and bringing this forward today. He also shared that there is some great from pharmacy in East London around accessible culturally based labelling of medication in Urdu or various languages.

Hassan shared that Sheffield have a very large Roma Slovak community. Other languages include other European languages and raised the need to move it forward and to increase the number of languages available. He is happy to work jointly with Dave.

Madeline Cooper shared the link below.
https://www.communityempowermentnetwork.org.uk/

Alex Clark raised that she has come up against similar issues in Cornwall and asked if there are any plans for developing a Ukrainian leaflet

Robert Ferris thanked Hassan and asked what more the Senate could do as a Senate to accelerate the work in diverse communities. In Birmingham for instance there are approximately 150 different languages and ethnicities. We do not have culturally sensitive and nuanced services that meet those that population's requirements.

Wendy Ruck added that this is an issue of representation of different ethnic backgrounds within the workforce and shared that Art therapy professions are looking at this in terms of access to training opportunities etc.

Sandy Bering thank Hassan for his presentation. He raised young black Afro Caribbean boys are over restrained and over medicated and the need to develop different options to add to these Hassan agreed there is a need for a flexible approach and shared that by using the voluntary hubs within different communities we work in is key to help us understand the needs of the communities and ensuring our services are flexible.

Restrictive interventions and what next re LTS / seclusion / solitary confinement /Hollins report – Leanne Gelder

Leanne reported that the independent care and treatment reviews have now restarted. This was one of the recommendations from the Baroness Hollins report.

In brief the Department of Health and Social Care led this programme previously and the recommendation was that CQC would run phase three over a two year period. This has now started and they are working closely with CQC to ensure a robust handover.

As part of that work they have established an Oversight Group to help in terms of thinking about the impact of ICTRs and the difference that it will make.

One of the one of the other key things linking into the recommendations is the work they are doing with colleagues in patient safety and the proposal that long term segregation, as well as some other forms of restrictive interventions, become patient safety events as part of the Patient Safety Reporting Framework.

Regarding the CQC notifiable events. One of the proposals within that is that restrictive interventions identified within the use of force that has become a CQC notifiable event. Leanne urged senate members to share their views on this as it is a significant change. Leanne advised that in principle they are in support of anything that increases focus on restrictive interventions, but highlighted the need to be mindful about balancing that out with reporting fatigue and risks and thinking about what is then done with that data once it is received. i.e. ensuring that whatever is put in place is meaningful.

They are currently working on the restrictive intervention data, as part of the Mental Health Services Data Set (MHSDS) and raised that there are some issues with reporting around restrictive intervention data, although she is pleased that it is has now been published again.

There is also a lot of other work happening on in the Quality Transformation Programme specifically culture of care programme. This is a 2 year programme

You know the kind of real focus on culture change and that two year programme and one of the measures they will be looking at as part of that will be the impact on restrictive interventions.

Questions

Briony asked whether there is a definition around what restrictive intervention is. Leanne replied that some are more clearly defined. For example in restraint there are definitions such as he Mental Health Code of Practice within the use of force. She shared that one of the pieces of work they are doing in NHS England currently is looking at defining 8 different types of restrictive practices. She stated this is not a straightforward piece of work and they feel it is important to have a shared understanding to build on it.

Leanne Kennedy queried whether there is a definition about practice of restricting access to food ie locking kitchens, locking cupboards and fridges?

Marie Lovell shared the following link
https://www.gov.uk/government/speeches/positive-and-safe-reducing-the-need-for-restrictive-interventions

Briony shared that Alex Ruck-Keen, advised it is not DOLS, its BI, and if all do not agree then it needs to go to the Court of Protection.

Leanne Gelder shared that one of her colleagues also leading on some of this work focused on community settings for Learning Disability and Autism and would be happy to come to a future meeting if this is helpful. Dr Roy asked Leanne to let him have the details.

Briony reported the National Guidance on Carer's Knowledge of Nutrition and we need a National Guidance to improve this.

Marie Lovell said that the (SFC) would be keen to be involved and have funding and capacity. They also have an expert advisory network of around 70 people with experience of using health services, which can be used to invite people to work in co-production

Professor Mary McCarron in the principal investigator for IDS-TILDA. And he is happy to invite to this meeting. He would also like to suggest her as a potential future keynote speaker for the Senate conference (see link below)
https://idstilda.tcd.ie/people/mccarrm/

Vivien Cooper shared the link below
https://www.challengingbehaviour.org.uk/information-and-guidance/when-things-go-wrong/trauma-support/

She reported people are traumatised by tyring to get support for their families. People with LD have greater mental health needs than the general population and we need to formulate the case in a simple way. She is happy for Jonathan to join in with this.

Ashok stated the need to not spending money early on. All money spent is usually health money. Maria Lovell agreed with Ashok.

	Marie shared the linked below which are under 'Identifying workforce learning and development needs examples' which try to describe people's possible and probable routes and includes a template to adapt to individuals or sections of the population https://www.skillsforcare.org.uk/Developing-your-workforce/Care-topics/Learning-disability/Learning-disability.aspx. Wendy Ruck asked how we promote the work of the Senate as many of her colleagues are unaware of the Senate or the details of the work undertaken. She is also not sure that the BILD website is working as well as it could do in terms of communicating the work of the Senate. Viv confirmed that a group of organisations have written to all the political parties and that Ashok was part of this. They have also met with the Liberal Democrats and have suggested a line on Learning Disability and will try to arrange another meeting. Jonathan advised that election 3rd sector organisations can advocate about the size of the gap and what are we doing about this. Ashok asked whether it is work meeting up to try and get a more defined message as we do not want to lose this thread. Jonathan agreed there should be a one off meeting and asked for people to express interest. Briony expressed her interest and agreed to write to Jonathan and Ashok
6	**New Items for Discussion**
	Public Mental Health Implementation Gap – Jonathan Campion Ashok welcomed Jonathan to the meeting Jonathan thanked Ashok and Viki for inviting him today. Jonathan introduced himself as the Director for Public Mental Health and a Consultant Psychiatrist at South London and Maudsley. He is also the Clinical and Strategic Codirector of the Royal College of Psychiatrist Public Mental Health Implementation Centre and a Public Mental Health Advisor to Europe. One of his actions is to improve the coverage and outcomes of interventions, both to treat mental disorder, prevent associated impacts, and to prevent mental disorder from arising and to promote well-being and resilience. People with LD are several fold at increased risk of other mental disorder and have high rates of physical illness and therefore require more targeted approaches to prevent widening of inequalities. He advised that we are fortunate because we have effective interventions for Mental Disorder and people with Learning Disabilities to prevent associated impacts. This is by a broad range of organisations. The challenge is the implementation gap. In England, only a minority of people with a mental disorder (apart from psychosis) get any treatment. There is an larger implementation gap for the prevention of associated impacts, and a negligible implementation of evidence based interventions to prevent Mental disorders or promote well-

being and resilience and this has huge impacts in preventable human suffering, impacts and associated costs. This breaches right to health and She statutory Duty under the Equality Act not to discriminate against people with mental disorder, and advised there are opportunities now to address this.
There are several Statutory Duties under the Health and Social Care Act that, as clinicians, we often are not aware of. However under the 2012 Act, CCGs and Local Authorities had a Statutory Duty firstly to assess the size of unmet need in their localities and secondly to prepare a joint health and well-being strategy to address the need. This was not optional but statutory.
Two years ago, under the 2022 Health and Social Care Act Integrated Care Partnerships also had statutory duties to assess how need is going to be met by the ICB. Partly Local Authorities and NHS England through the Integrated Care strategy, and that included people with Learning Disabilities.

Jonathan shared that he has been doing a large amount of need assessments across the country which has found that people from high risk groups are generally neglected, and this includes people with a Learning Disability. These people are at a disadvantage not only in terms of this advocacy instruments but it is also breaching the Health and Social Care Act. There are several opportunities. Firstly, support for local public health teams, who usually carry out these assessments, to highlight more prominently the needs of people with Learning Disability. Secondly there is a need for a national assessment of people with Learning Disability. This would inform National Policy to address the gap in line with Statutory Duty and the right to health. It would also support, the inclusion of a broad range of stakeholders, people with learning disability, their carers, and also a range of organisations to agree what would be an acceptable level of coverage, to plan it over the next five years.

Jonathan shared that he has had discussions with Ken, with Ashok and it would be good to have the thoughts, comments and advice from Senate members about such a proposal.

Ashok thanked Jonathan and added we have talked a lot about proactive care early interventions in pathways, multi-agency inputs and non-pharmacological approaches. We know these are important but feels we often lack scientific rigour, evidence of effectiveness/evidence of need and that is the reason he felt Jonathan will be an important in helping to shape our thinking as a multi-professional advisory group. in making the argument we often lack evidence

Siobhan Rogan thanks Jonathan and explained she works the Public Health Agency in Northern Ireland, and is very interested in this agenda. She added that we absolutely need this as when we go to develop any policies around people with a learning disability and meet their needs, it's very hard in one place to find out what the actual needs are and feels we are not taking a preventative approach or population levels, interventions and very often these groups are excluded.

She also raised The Irish Longitudinal Study on Aging (TILDA) and felt that we should get someone to come and speak to the Senate around their findings. There are some interesting differences in the age and health of people with the learning disability and the inequalities. For example 85% of people are attending a dentist, but they're not getting treatment – there is a lot of people attending but it is not translating into treatment, which actually has huge impacts on the person's health in other areas. She added anything they do if Northern Ireland can be included in it. Otherwise there are going to be 4 countries coming up with different information.
The South Ireland are the only country in the world that is gathering information about ageing of people with a learning disability but there is an opportunity to be included and she would like to embrace this opportunity.

Ashok agreed that this is an extremely useful resource and we need to discuss how the information is conveyed to this group. He asked Siobhan to provide the names of contacts of key people

Action: Siobhan to share the names of contacts/key people with Ashok

Questions/Comments

Jonathan thanked Siobhan for her enthusiasm. He stated that Public Health is a key sector that often clinicians do not have close connections with particularly around the understanding of what the size of the unmet need. Public Health is a critical part of the implementation of these interventions. This is why there is a need for a joint approach. In terms of localities and local authorities, resources actually decided at national level and when you have a range advocates from different sectors for example from people with learning disability, their carers this coordinated approach in his experience can more powerful at a national level.

Ashok raised that Vivien Cooper, from the Challenging Behaviour Foundation has strong links with family support groups and is better than we are at campaigning for various priorities and a partnership between professionals and such groups would be more impactful.

Vivien Cooper raised the importance of identifying people with needs and to meet those needs in a timely way and that does not happen. She highlighted that there are a lot of ways the system is organised to work for the system rather than for the people that it is meant to be there to support. She is happy to work with Jonathan to think about anything we can do that will be useful and helpful.

Ashok thanked Vivien. He also raised that is the use of people with experience of using health and social care services.

Marie Lovell shared they have a register of approximately 70 people who identify themselves as having an interest in Health or Social Care and is happy to invite these people on behalf of other organisations or send out invites. As families with people who need more support than the average family member might need for example, families with autistic family members or family members with Mild or Moderate Learning Disability who are in their late 20s, 30, 40s the way social care works now, in her experience is that if you people are coping they are not eligible for anything and people have to reach a point where they are in crisis, they are not in a good place and broken to get the help of services.

Jonathan thanked Marie and said he would be happy to meet with her. He shared that he has personal experience of this and that has also been his experience. He feels the voice of people with Learning Disability and how that is captured is critical. He shared that he is currently finishing a mental health need assessment for a very deprived borough in the north of England for children and young people and there is very little information about people with Learning Disability to inform the needs assessment and therefore there is an immediate gap. Interestingly when he engaged with a broad range of children and young people and asked what is the level of coverage, for instance, what proportion of people with a with a mental disorder should get treatment they answered 100%. This information is helpful because currently the NHS England target is 35%.

Ashok picked up on what Jonathan had raised earlier with regard to money and said that there have been millions of pounds spent dealing with failed care packages and wrecked lives. It is evident that a pound spent early on in the pathway would save thousands of pounds down the line.

	Jonathan felt that the overall resource should be improved and agreed with Ashok that we need to be thinking much more upstream, which also requires appropriate resource. Viv stated that the Senate has a strong voice and has huge knowledge and experience collectively. It was agreed that the Senate should meet to review future direction. David Standley shared the link below. https://acppld.csp.org.uk/news/2024-05-06-role-specialist-learning-disability-physiotherapist-animation-launch Jason Crabtree shared the website BILD have for the Senate is outdated (see link below) https://www.bps.org.uk/guideline/psychologists-promoting-and-supporting-physical-health-people-learning-disabilities
7.	**Date of Future Meetings**
	Future Meetings: 2nd September 2024 9:00am -12.30pm 2nd December 2024 9:00am -12:30pm **LD Senate On line Conference 17th October 2024** **LD Senate On line Trauma training event 13th November 2024 10:00am-14:30pm (timings tbc)**