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**Learning Disability**

**Professional Senate**

**MINUTES**

**Learning Disability Professional Senate**

**Meeting held on Monday 4th December 2023**

**09:00am to 12:30pm via MS Team**

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|  | **Welcome, Introductions and Apologies** |
|  | Prof Roy welcomed all to the meeting and introductions were made |
|  | **Minutes of the last Meeting** |
|  | Following amendment to the final paragraph under section 6.1 – Policy Related Updates requested by Dave Nuttall the minutes of the meeting held on the 4th September 2023 were agreed as true record  **`** |
|  | **Action Log** |
|  | The Senate action plan was shared and updated – (see below)    **LeDeR report** – has been published.  **Positive support meeting** – is being set up.  **Obesity PP update** - After some reflection following the comprehensive feedback from Scotland it was felt as though the position statement needed to take a different angle, one that was more steeped in evidence and connected to  other national guidance such as <https://www.gov.uk/government/publications/obesity-weight-management-and-people-with-learning-disabilities/obesity-and-weight-management-for-people-with-learning-disabilities-guidance>  Whilst acknowledging the amount of work that has already taken place, yet being realistic with the time that is required to amend the current document we have agreed the position statement is postponed until the spring and Briony will be in touch with colleagues.  Senior intervenor programme – pilot phase completed.  HOPE(S) pilot runs to December.  Handover between services - in action log |
| **4.** | **National Updates (9.30 -10.30)** |
|  | **Dave Nuttall – Department of Health and Social Care**  **Long Term Segregation**  Response to Baroness Hollins report on reducing the use of LTS for people with LD and Autism and the Government response - was published on the 8th of November 2023. Response to this as follows: -   1. Transfer of the ICTR Programme over to the Care Quality Commission. So far 2 phases of ICTRs have been completed and a there has been a lot of learning around how the processes have run, what has been good, what could be stronger. One of those those elements is ensuring there is a clear connection with the work of the regulator.   This work will be recommencing again in the coming months and will be run for the next 2 years.   1. Proposals to reform - some of the CQC regulations to make the use of LTS a notifiable event to the CQC of the CiTR process, proposals to guidance to make LTS a notifiable event to CQC to improve reporting/information and governance.   Other programmes currently underway are Senior Intervenor Programme – continuing to work with people who are being supported to move them out of restrictive settings and toward discharge and the HOPES Programmes. When work commenced around ICTRs with Baroness Hollins and the Oversight Panel. This was intended to be a swift piece of work however COVID happened and the impact of that was that a first round of reviews was carried over a range of different methods including hybrid and virtual components. It was reported that when they got to the end of the first round it was clear they still needed to continue to review people’s care and the second phase was commissioned.  **Questions/Feedback**   1. ***Viv – Are there any proactive actions from learning from the ICTR report supporting people before they get to solitary confinement.***   Dave stated all of the lessons they have picked up through doing ‘building the right support’ and transforming care before that apply equally in these circumstances. One of the common features is that some people have been inpatients for a very long time and predates some of the work that has been going over recent support. Inevitably it is better to get the care and support in earlier. What they have trying to do with HOPES programme is to change cultures and approach. Senior Intervenors is about trying to get a person in who is a consistence presence and links together all of the statutory bodies and partnerships who might be involved in helping that person into better circumstances. Senior Intervenor and HOPE(S) work will be evaluated before drawing lessons about what the next step will be. There were a series of things identified by Baroness Hollins and the Oversight Panel which require some revisions to the Mental Health Act Code of Practice.   1. ***Prof Roy raised whether the 2-year extended process would be linked to the Senior Intervenor programme and is that also for 2 years.***   Dave advised regarding the Senior Intervenor, Programme the commitment has been made that people who had been supported by a Senior Intervenor would continue to have that support and the pilot phase has been completed. The HOPE(S) model pilot runs to December 2024. The ICTRs is a 2 year Programme and is currently being recruited to and set up. This work will be carried out by working closely with NHS England and will look at how they all interact as well before drawing lessons about what the next step is.   1. ***Viv raised all the things that have been discussed have been after people are in Long Term Segregation and asked whether the department are looking at the long term whole lifelong trajectory as it is difficult to see where the actions are addressing problems early i.e. proactive approach rather than reactive.***   Dave feedback that programmes such as the HOPE(S) Programme are not exclusively about working with people in long term segregation, they are also about changing the culture and approach to stop some of the progression into long term segregation for some people. The wider work on quality improvement in inpatient settings is about reducing the use of restrictive practice and looking back at the case history and posing questions around what might have happened in different circumstances which goes back to building the right support space, and work going on looking a housing support and looking at different aspects of care. These are not dealt with as separate processes they link across with people working on both sides to ensure we import lessons from the learning around LTS into building the right support.  **Feedback from Leanne Gelder - Specialist Advisor of Quality Improvement**  Leanne raised it is critical to look at both prevention and understanding of the patient journey i.e. how people get there in the first place. A lot of work has been done to move people out but looking at the overall numbers there are still people moving in. Regarding the HOPE(S) model one the things they have been able look at in terms of supporting the system is the culture that leads to a higher use of Long Term Segregation (LTS) in some areas whilst in other areas LTS is not used at all. To build on what Dave said earlier in terms of quality transformation there is a huge piece of work they will be starting in January 2024 around culture change and restrictive practice.  Dave reported that one of the things that that has become clear over the last four years is the importance of data and understanding what is happening. In 2018, individual localities and regions may have been aware of where LTS was being used, but not the national picture which is why it is important the CQC lead on it. When it was headed up by the Department there were challenges in terms of flowing some of the information around within the data protection rules and within appropriate information governance and the CQC’s Regulator can gain access to the information much more quickly. Regarding regulation reform its about having swift access to the right information to be able to take action quickly and promptly which is important in order to be able to take action and start to draw that learning locally around what has been happening. Dave asked all present to look at the report and the links within the report.  **Oliver McGowan Mandatory Training**  Consultations have been closed, one in standard format and one in easy read on the code of practice for Oliver’s training and have proceed this and will be publishing a response and will revise the code if revisions are necessary.  A couple of weeks ago there had been 1 million completions of the e-learning part of the training, which is phenomenal in terms of numbers required in order to make the impact and the change on practice. Face to face Tiers 1 and 2 have now started rolling out.  The feedback has positive and there have been a lot of powerful vignettes and stories about how people have been doing the training and how it has led to changes in practice.  The Department are focusing extensively on what is the correct model for adult social care, whether or share of the features or is it completely separate to that which is being used within the NHS.  **Down Syndrome Act implementation**  There is a lot of work being done in developing the draft guidance which is required under the Down Syndrome Act. The Guidance will set out how to meet the specific needs of people with Down Syndrome in the various domains covered by the Act, i.e. health, social care, housing and education and likely to also touch on other areas including employment support.  The Guidance is currently being produced and the draft will be issued early next year for full public consultation. The update to the Autism Act Statutory Guidance, shares many features with the Down Syndrome Guidance and is also being produced.  Regarding work on children and young people. The launch the Partnership for Inclusion Neurodiversity in School Programme (PINS). The PINS Programme is backed with additional funding is about getting early support into schools and upskilling staff to be able to support neurodiverse children building on the successful Autism in Schools’ Programme. The intention is to try to get early help and upskilling to reduce queues for services. This has been funded for 2 years working with 10% of primary schools. They are also in the process of working NIHR and are looking at a bid for research into demand for therapy as part of SEND Improvement Plan    **Building the Right Support**  Ahead of the March 2024 date there are a couple of key items ensure the action plan is taken forward and completed. They will also be looking at and trying to understand some of the trends within the data. NHS England have published statistics which demonstrate that within the headline numbers there are some very different trends for different groups within the population with significant decreases in the numbers of inpatients who have a Learning Disability but are offset by an increase of inpatients with Autism without a Learning Disability who are admitted into mental health pathways.  **Question/Feedback**   1. **Prof Roy asked for clarification around what will happen with the various Acts which were not acknowledged as part of the King’s speech. There will be a lot of people who are gearing up for a very new approach to things, who will now be wondering what they** **do with half written guidance and half written codes of practice etc**   Dave acknowledged the disappointment regarding what was exempt from Kings Speech but felt that the intent remains to bring forward the legislation in due course. There is a Draft Bill on which there has been a lot of work and the next step will be a response to the Scrutiny Committees Reports. This remains outstanding as there is still work required on the Draft Bill.  In terms of next steps one of the things they will be looking at is what elements can be progressed in the absence of legislation in the near term.  [*https://www.hssib.org.uk/patient-safety-investigations/caring-for-adults-with-learning-disabilities-in-acute-hospitals/investigation-report/*](https://www.hssib.org.uk/patient-safety-investigations/caring-for-adults-with-learning-disabilities-in-acute-hospitals/investigation-report/)  **Wanting know next steps from NHSE perspective , Leanne shared the following report.**  <https://static1.squarespace.com/static/58d8d0ffe4fcb5ad94cde63e/t/653fb597472c6f26c0adfb46/1698674072786/Year+4+National+report+FINAL.pdf>  **Questions/Feedback**   1. ***Viv - asked when the that response to the recommendations is likely to be published.***   Dave responded he couldn’t answer that question. He will check and feedback.   1. ***Kirsten – asked for clarification around the Health Services Investigation Board report, the shared roles of NHS England and the DHSC around this and who takes responsibility for what, particularly in relation to funding***. 2. ***Another questions was around the Learning Disability Improvement Standards and benchmarking in Acute Hospitals the funding for which is due to come to an end at the end of this financial year as one of the recommendations was that it should be continued and be long term funded. She raised that the report published in November suggests that its NHS England's responsibility.***   Leanne replied she is aware of the recommendation contained in the NHSE report and are committed to taking the standards forward. They have commissioned NHS benchmarking to undertake an impact assessment alongside year six year (which is the year we are in currently and is the final year they had committed funding around). One of the things they want to look at longer term is whether they should be focusing on all of those but there is a lot of evidence pointing to the benefit of them in terms of physical health settings and whether it will be about looking in that around specifically. She acknowledged and apologised that publication had been delayed. Year four has been published quite recently and year five is due for publication imminently and she will feedback as soon as she has a date.  **Question**  ***Lucy - raised there is a section 3 in the report on workforce that does not relate back to any tangible links to workforce in our national programme. If it continues, she would like to have a conversation.***  Leanne advised Lucy she will cover workforce further during her discussion on the agenda.  Prof Roy thanked David for his feedback and said this is a high priority for all of us. |
|  | **Catriona Jamieson/** **Senior Educator MHLDD/NMAHP/ NHS Education for Scotland**  Catriona introduced herself to the meeting and gave apologies for her colleagues Isla McGlade and Samantha McEwen who had not been able to access the meeting as she had not been invited.  Catriona gave an update on the work being undertaken by the Learning Disabilities work stream.  The NES LD Team (NHS Education for Scotland) are one of the boards within Scotland which supports workforce and education. The team was set up to address the specific workforce learning needs around people who have a learning disability.  The team are Audrey Taylor, Head of Programme and Occupational Therapist, Jill Jones, Head of Programme, Clinical Psychology and Dr Allison Dougall, Principal Educator and Clinical Psychologist, Dr Doug McConaughey, Principal Educator and Clinical Psychologist, Claire Wakefield, Clinical Educator and Advanced Practice Occupational Therapist, and Rakesh Upadhyay, Principal Educator and Lead Physiotherapist, and herself Catriona Jameson, Principal Education and LD Nurse.  Catriona explained the team are involved in multiple projects, including looking at work already being undertaken throughout other directorates but for the purpose of this meeting, she will be concentrating on one aspect of their work, the essentials of learning disability. This was developed from a review of existing resources and conversations with the workforce around what their needs were post COVID. The existing resources required a considerable commitment to time from staff and services and their commitment was to transform learning, particularly for staff  who are new to working with people with the learning disability and which reflected changes and needs across Scotland. The essentials of Learning Disability consist of clusters of 30 to 40 minute modules at an introductory level. These are intended to provide learning, which is accessible, sustainable and practical. One of the main barriers identified was bringing learning into practice and being able to practice it with people who have a learning disability. Many of the  topics are interlinked and there are links within each module to further information more generic resources and more specialist resources particularly around conditions such as epilepsy, trauma and psychological wellbeing.  Within the essentials of learning disability, they have devised learning pathways throughout the topics for people who have different educational needs and who are in different roles to enable them to access resources tailored to them.  The plan is to complete the topics below in the first wave and then add to these on an annual basis of putting some links into further resources  **(see presentation below)**    **Question**  ***Dave Gerrard regarding the first flow chart presented, he had observed that there was no mention around medication. As the representative for the STOMP/STAMP Programme there are a lot colleagues north of the border who have made the link to say what transfers into the Scottish system and asked whether there are plans to pick this up within the work they are doing?***  Catriona advised that once they have the basics in place this will be integrated into the work.  **Scotland - Samantha McEwan**  provided an update and nursing review. A review commenced in August 2022 and was completed January/February 2023.  Recommendations, action plan and this implementation period runs from April 2023 to December 2024. **(please see presentation below)**    This review was carried out following concerns around access for employment for learning disability nurses, particularly across remote rural areas in Scotland. She explained they have quite a centralised delivery model for learning disability nursing education in Scotland. The two main providers are both located in the central belt one in Glasgow and one in Edinburgh. They also have Open University, but the numbers are very small (currently less than double digits).  The review was carried out to try and understand the impact of the delivery model on recruitment and to the education programs and progression through the programs and completion and then subsequent employment and NHS Scotland and what that would look like.  Prof Roy thanked Samantha for joining and requested her slides be shared for circulation with the minutes. |
|  | **Wales – Dr Ruth Wyn Williams**  Ruth provided an update on the following workstreams  **Learning Disability Specialised In-Patient Services**   1. TOR (draft) for the specialist LD Inpatient Focussed Review developed. 2. Four LD inpatient audit cycles completed – workshop in December to explore data, definitions, Pathway of Care Delay criterion and agree TOR for focused review. 3. Physical Environment review completed by National Collaborative Commissioning Unit – final report expected end December, 23 scheduled to present to CNO January 2024. 4. LD-NIAG (National Implementation and Assurance Group Adult Learning Disability Specialist) continue to explore how to capture health board transformation plans, reduce variation of NHS specialist LD service delivery across Wales, i.e., universal core offer of community services and Assessment & Treatment Units. 5. In the process of producing a national improvement programme proposal for reducing length of inpatient stay. 6. Learning Disability Quality and Safety Standards for adult LD services – work commenced towards the development of a proposal regarding the value of creating a set of quality and safety standards for adult learning disability services.   **Mortality Review and Medical Examiner Service**   1. Agreement reached of sharing data between WG, ME and Improvement Cymru/NHS Exec Wales. 2. Overview of mortality amongst people with a learning disability in Wales 2012 -2022 report expected end December. 3. Discussions with NHS Exec Wales to undertake LD themed review 2024. 4. We’ve looked at deaths of some people with a learning disability in Wales using routinely collected general hospital admissions data and death certificates. 5. Found a similar mortality age gap as in other UK nations using very different approaches. 6. Major avoidable or preventable causes of death of people with a learning disability in Wales include respiratory infections and cancer. 7. There is no sign of a reduction of deaths from intestinal obstruction or from dysphagia (and aspiration pneumonia etc.) amongst people with a learning disability in the last ten years.   **Learning Disability Education and Training Framework**   1. The Foundation Phase of the Paul Ridd Learning Disability Education and Training programme was launched in April 2022. The training is mandatory for all NHS staff in a public facing role, over 40,000 NHS staff have undertaken this training (data up to June 2023). Continue to monitor uptake across Wales. 2. Work commenced to adapt and update this training for use within social care and across the wider public sector with a view to launching this formally early next year. However, the training is already available for non-NHS staff should they wish to complete it and can be accessed via the Learning@Wales website or via Health Education and Improvement Wales (HEIW) Ty Dysgu platform. 3. Recently commissioned HEIW to develop the Tier 2 Enhanced and Tier 3 Advanced training programmes for those with more frequent, direct or specialised contact with people with learning disabilities. This training is expected to be available in late 2024/early 2025.   **Learning Disability Health Checks**   1. Each health board receives additional funding to assist them in improving access to and frequency of the number of health checks being offered to people with learning disabilities. Each health board has adopted a different approach as to how they utilise this funding and have committed to reporting back to Welsh Government on its utilisation and effectiveness with a view to helping shape the future format of the health check process. 2. Welsh Government currently in the process of developing plans for a cluster-based approach to the delivery of LD health checks, moving away from a reliance on a GP led service with a specialised Direct Enhanced Service contract. 3. Working on the development of an electronic health check that can be utilised by any appropriately trained health professional across Wales.   **Development of a Digital Health Equalities Framework (HEF)**   1. The Service User Outcome Tool report has been shared with HEF leads in the health boards. Currently exploring recommendations from the report to identify a way forward to test in practice. 2. Translation and validation of the tool into Welsh ongoing. 3. Digital development - Findings and outcomes of the Alpha phase shared with health HEF leads and champions and next steps explored.   **Improvements to Physical Health Provision**   1. Progressing with the validation of a bowel screening tool and planning to establish a special interest group. 2. Working alongside the Public Health Wales Vaccine Preventable Diseases Programme (VPDP) on a vaccine project for people with a learning disability. Launched as part of the Autumn/Winter 2023 campaign. 3. Waiting final report of the Once for Wales Health Profile evaluation, once this is received we can consider its finding and recommendations to increase the ownership amongst people with a learning disability and their families and to promote as a patient safety tool within health care. 4. Establishing links with organisers of NHS Wales app to ensure a link to identifying people with a learning disability and also looking for ways to capture people with a learning disability and their health profiles within the Welsh Nursing Care Record. 5. Ongoing discussions with Welsh Ambulance Service NHS Trust in respect of their Electronic Patient Record and its capacity to flag for reasonable adjustments for all individuals they respond to with a learning disability across Wales. 6. Final report reviewing the LD Care Bundle imminent, findings and recommendations to be considered to improve acute hospital care for people with learning disability. 7. Continuing work to understand role and function of Acute Liaison Nurses in Wales and support and facilitating national meetings. Work continues on the Dashboard to gather data in addition to ongoing discussions with ALNs to plan implementation and evaluation.   **Children and Young People with a Learning Disability**   1. Commissioned a literature review to evaluate national care models and frameworks providing care for children and young people with a learning disability in Wales. This has been completed by Wrexham University. 2. Two proposals have been developed for pieces of primary research to be completed in support of the literature review which will explore the Children & Adolescence LD Service model in two health boards. 3. Continue to grow and mature a community of practice across all public sectors with a specific focus on learning disability services for children and young people, membership is up to 430 members with the development of a subgroup specifically for parents and carers being established. 4. Following a successful grant application process, six improvement projects commissioned to explore innovative ways to improve service delivery of health and social care for individuals with a learning disability. 5. A series of direct school engagement sessions with special schools are planned to meet with the pupil council and gain feedback from the children and young people in regard to what they would like to see within a national vision.   **Next Steps**   1. The LD Strategic Action Plan work has commenced on a review and refresh of the plan ahead of publication next year. 2. Welsh Government engagement events - undertaken a series of in-person engagement events across West, North and South Wales, meeting directly with people with learning disabilities, their families and carers to ensure we hear directly about the issues that matter to people with lived experience. Currently analysing and theming the data captured. 3. Review LDMAG - reviewing and refreshing the structure and membership of the Learning Disability Ministerial Advisory Group to strengthen its role and ensure it is fully representative with the knowledge, skills and expertise necessary to operate effectively at maximum potential. This work is also set to be complete by the spring of 2024 4. Strategic planning with NHS Executive - first all stakeholder workshop to explore an LD safety and quality programme for Wales 05/12/2023.   **Questions/Feedback**  ***Viv fedback stressed that the work the National Implementation Group are doing to reduce variation is an important thing for families they support as there is a huge variation depending on where you and what is available.***  Ruth acknowledged this and shared that they have representation from the Local Authority and Health and the work is progressing well. David O'Brien from improvement Camry is part of the group that implements this and suggested Viv could link in with him.  Viki – thanked Ruth for the brilliant update and asked whether she had a written record she could share for the minutes |
|  | **Northern Ireland – Siobhan Rogan, Assistant Director for Learning Disability and Mental Health**  Siobhan reported The Restrictive Practice and Seclusion Guidance was launched in March of this year and they are now moving towards implementation. She advised they have come across some challenges particularly from providers saying they can no longer meet the needs of people with an intellectual disability, specifically citing that they are allowed to do things in other parts of the UK that they cannot do in Northern Ireland and that is around seclusion outside of the hospital setting and there is some concern about that. A new term is developing called ‘handbags’ where care packages have been handed back over to Health and Social Care Trusts from independent sector providers, and although this work at an early stage there is a concern.  Siobhan echoed what Leanne had highlighted earlier, that this is a cultural issue that needs to be addressed and changed within the system. This could impact on the resettlement programme, and she would be interested in discussing this further with other members of the Senate. An emerging issue is that although people are not being secluded in hospital at present, providers may say we cannot take this person and care for them outside of the hospital setting because we cannot use seclusion.  There is also a significant piece of work around the Learning Disability Services Model. Siobhan explained that in 2018/2019 there was a lot of transformation to develop a new Adult Learning Disability Service Model for Northern Ireland. This work was coming to an end when Covid happened, and the Department of Health have undertaken a review piece of that work and have  extended it to include children services. This is about reducing the variation so that there is a single offer for Northern Ireland. It is slightly different as health and social care are integrated.  **There are 6 themes of Key ambitions**   1. **Life changes/transitions** 2. **Health and Wellbeing** 3. **Carers and Families** 4. **Meaningful Lives and Citizenship** 5. **Home** 6. **Mental Health and Behaviours.**   Siobhan highlighted mental health and behaviours has been one of the most challenging in terms of getting people within Learning Disability Services to view themselves as a Mental Health Service within Specialist Learning Disability Services. She explained it has become very apparent that there is a real misunderstanding of the role of inpatient care within the system and feels that this needs to be addressed. She also raised that people at quite senior levels feel challenged by a change around this. The expectation is the work should be completed by March 2024  The Muckamore Abbey Hospital Investigation and Inquiry is ongoing. As far as she is aware some charges have been made but there have been no court cases to date. The inquiry resumed after the summer and has heard a lot of evidence from families and carers and are now starting to hear evidence from staff. These are people who have put themselves forward to the Inquiry at this stage they have not called members of staff or any other witnesses so far. They have from organisations such as the Department and Trust, but not individuals. This will be ongoing.  Linked to the Restraints and Seclusion Guidance, the Department of Education recently put out a guidance for consultation on restraint and seclusion which had very significant implications for health and social care staff and was quite at odds with their  social care guidance. They have not had sight of the outcome of that consultation, but they are aware that a number of professional bodies and organisations put a response into that saying you can seclude children in school in the Guidance. She felt that they were surprised that people were upset about it.  There is also a consultation ongoing around the review of children’s social care which is relevant to this this group as despite it being a review of children’s social care, where the recommendation is an arm’s length body. They have looked at the role of IVY (Interventions for Vulnerable Youth) which is their inpatient CAMHS Service for children with an intellectual disability and have questioned the role of it. They have also queried whether CAMHS should come into Children’s Social Care Services, or what is described as the non-clinical part of CAMHS despite it being a Mental health Service. This consultation closes next week. She is also aware a number of the Royal Colleges and other professional bodies are put in responses into that.  They are also looking at ASD and ADHD pathways. There is a significant demand for these services which is outstripping availability of services and they are seeing children waiting for five years for an ADHD diagnosis and they are trying to look at ways to improve that  In terms of our mental health strategy the CAMHS needs of children with an intellectual disability,  there’s a reference made in there and a recommendation made and CAMHS have made the development of those services in Northern Ireland their first priority and they are starting very early stages of work in relation to this. |
| **Break 10.30- 10.40** | |
| **5.** | **New Items (10.40-11.40):** |
|  | **Katharine Peterson – Forum Family Practice**  Katharine is a GP in Cramlington, Northumberland and is the clinical lead within the ICB and Northeast, North Cumbria in Learning Disability and Mental Health Neurodiversity in Children.  Kathy shared her presentation **Adult not Brought** and described it in detail  **(see presentation below)**    [Prevention of Adult Not Brought Strategy « Learning Disability Network (necldnetwork.co.uk)](https://necldnetwork.co.uk/work-programmes/reasonableadjustments/panb/)  In summary, patients without capacity or capability may not be able to bring themselves and they can now differentiate between this in their notes, and use reasonable adjustments to mitigate this across health and care.  **Questions/Feedback**   1. ***Prof Roy praised Kathy for the amazing work she has done on this project.*** 2. ***Viki shared that when Kathy sent the slides to her she thought they were brilliant and how much that should speak to across all our services. In terms of this awareness the work Kathy has done in identifying those at risk groups and the profile raising of difference between DNA gives extra emphasis to that. She felt that looking at that list around why people may not be being brought to appointments and linking it to social deprivation is extremely important.*** 3. ***Siobhan Brennan shared that she felt it was fascinating. Going back to what Kathy had said regarding flexibility of setting one of the priorities they attempted during Covid was remote appointments. However, what they found was that the entire delivery of the care, even when it was a discussion appointment, the emphasis moved away from the individual themselves and onto the carer because they were the person who happened to be using the device. There was also very little guidance around in terms of how to you could maximise remote appointments.*** 4. ***Linked to poverty, appointments which depend on technology may not be an appropriate for a lot of individuals. Should there be more guidance around remote appointments and do you think this is warranted for these particular families?***   Kathy thanked Siobhan for raising this interesting point and felt that it would depend on the carer/the family for some people. They may not have credit on their phones or just do not have the ability to use the data that they have on their phone, and we have to consider digital exclusion. Furthermore, a lot of their patients live in the lowest quintile of deprivation and she feels we need to be realistic about these thing..  She further advise that In her practice they start with how they interact with patients, which fits best for everybody and explained that for her it is around total flexibility i.e whatever, suits now.   1. ***Jason Crabtree shared it was interesting to see where Kathy’s thinking has led and what sparked it. He also felt that the Universal Care Plan will segway nicely into this. He asked whether she had thought about the use of hospital passports and where they will fit?***   Kathy acknowledged hospital passports are important however the challenge in both primary and secondary care   1. keeping the passports up to date 2. keeping patients engaged 3. having time to read and embed them into our reasonable adjustment flag.   Another thing to consider is a carer may have five appointments that week for a patient.   1. ***Sue Hastewell fedback she really enjoyed the presentation and is heartened to see something is being done regarding appointments. She asked whether Kathy had picked up on people who live in supported living? They have come across some cases where somebody is off sick, or a member of staff just did not take them to the appointment and it is registered as a DNA?***   Kathy responded that she works in a practice where they have a supported living environment for patients with learning disabilities. They also have a care home for patients with dementia, the frail and elderly. What she consistently sees is simple human error, for example   1. letter it typed and is sent to the patient, the patient keeps the letter but it does not get communicated to the manager and hence it is not entered in the diary, 2. staff have the letter but the appointment has been entered in the work diary. Sometimes these errors just needs highlighted and supported.   Kathy advised she is happy to support anyone who wants to discuss this further. If anyone has any further questions they can email her directly.  Prof Roy thanked Kathy and stressed that this is such an important topic we need to work out how we keep it alive and weave into other things that we do. |
|  | **Leanne Gelder – Restrictive Practice Oversight Group**  **(see presentation below)**    Leanne shared her slides which advised on what they are doing around restrictive practices within NHS England. This is primarily focused on inpatient mental health, learning disability and autism settings as part of our overall quality transformation programme. This is a 3-year programme and their aim is about improving quality and safety of care for people in inpatient settings across mental health, learning disability and autism. There are several key themes they are focussing on in order to achieve this. (a link will be added to the chat with information members can look at regarding this on the web page)  One of these themes is about culture of care and how important it is to think about culture of care and reducing restrictive practices together, recognising that if we can get the culture of care right, we should see a reduction in restrictive practices. Within their culture of care work they have co-produced some standards around culture. They have not been published yet and are not  available externally to the NHS. (They have been uploaded to their Futures Platform and a link will be added in the chat to share this)  The third commitment is around relationships and how we prioritise trusting relationships. There is evidence that the biggest indicator of improved outcomes for people is the therapeutic relationship that the people we care for hold with the people looking after them?  Some of the headlines of the work that we're focusing on is about how we can support people to implement at the Statutory Guidance and the use of Force Act. She highlights that there have been some challenges for people in terms of how to put that into practice and interpreting some of the guidance and in particular thinking about settings that may be more complicated in terms of whether the acts should apply or not, particularly around acute physical health settings where people may be being treated for things that might be associated with their mental health difficulties. They are working with the Department of Health and Social Care, and the key focus over the next 18 months to years is to think about how we can support people.  The aim of the Reducing Restrictive Practice Oversight Group is to ensure that they learn from things that have already happened or are already happening, i.e thinks like the HOPE(s) initiative has been running for some time now is due to conclude December 2024.  There has also been a huge amount of work done through the Mental Health Safety Improvement Programme which concluded in April 2023 which focussed on reducing restrictive practice. The National Centre for Collaboration for Mental Health led on this, and they are publishing some of the findings on their website.  Work is also going on in the programme around early warning signs and restrictive practices has key part to play in that around how we use data and information around that to help us flag when things are not going well and we need to be concerned and step in and offer support.  Lastly, but importantly is around how do we get to a position where we have a common language around restrictive practice. For example how do we and raise awareness of different types of restrictive practices and how we think about some of these definitions to ensure that we are not only raising awareness, but we are also talking the same language when discussing this.  Leanne shared she is happy to link up with people individually if there are pieces of work you would like her to be involved in.  **Questions/Feedback**   1. ***Jason Crabtree fedback he is aware that there are group of colleagues which cover both psychology and psychiatry who have raised some concerns about the LTS for some individuals with Autism and Learning Disabilities when on inpatient wards which are predominantly adult mental health inpatients and their needs may not be meet in terms of their care plan. The concern is that narrative about reducing long term segregation may actually be detrimental to people's experience. He asked whether Leanne is aware of this group and the work they are doing?***   Leanne replied she was not aware of this group and it would be good if Jason could connect her in terms of the wider issue. She also advised there is a big piece of work being done around redesign in terms of commissioning for inpatient services, which will think about things such as environment, sensory needs and reasonable adjustments.   1. ***Viki Baker requested people in their professional rules to link with Leanne on behalf of their professional body. Viki and Leanne had a conversation with the College of Speech and Language Therapists about how speech therapy could be involved in the various pieces of work.*** 2. ***Viki asked how we maintain a link with this group. There are so many pieces of work that is relevant to what we are doing in this Senate She also asked if Leanne should be a regular member of the Senate or do we encourage people just to link in with her individually around particular pieces of work?***   Prof Roy agreed Leanne should be a regular member and meet all the professions. This will avoid cross representations.  Prof Roy thanked Leanne her for her huge contribution today. |
|  | **Universal Care Plan – Jason Crabtree - Consultant Clinical Psychologist**  **Tower Hamlets Community Learning Disability Service**  Jason reported that part of his role has been the Clinical Lead for Learning Disabilities and Autism within Tower Hamlets as part of the North, East London ICB. One of the jobs he was tasked with a few years ago was to think about an electronic version of hospital passports developed from the Coordinate my Care Plan **(see presentation below)**      **Questions/Feedback**  ***Kirsten Lamb felt it is a great idea and it links with the whole hospital, passport work but felt that to just do this level of development in one region does not solve the problem as people do not live and move in one region.  The reasonable adjustment flag and the summary care record with additional information are universal within England and is held on the spine and the summary care record is constantly updated.  Her worry is around duplication and how we solve that problem.***    Prof Roy felt this was something we will need to think about.  He thanked Jason for the amazing amount of work he has done in this area |
|  | **Jason Crabtree - TW v Middlesbrough judgement**  <http://www.bailii.org/ew/cases/EWCOP/2023/30.html>  **There are no slides for this (see link below)**  Jason brought this judgement to the Senate as he felt it has some implications more broadly for those working in the field of learning disabilities. This was a Mental Capacity Act and Court of Protection around decisions of care and support. The outcome of this, and where it may have implications, is that the judge suggested that people are given a diagnosis of learning disabilities 'in line with the BPS Guidance' around the best practice in relation to diagnosing learning disabilities or 'not in line with the guidance'. Jason feels that this poses a challenge as the guidance reflects an articulation of the use of standardised tools to assess for the presence of  the diagnostic criteria for intellectual disabilities, as recognised by the NHS and in terms of international diagnostic classification systems. **(see link below).**  BPS are reviewing their guidance on diagnoses and have responded to this judgement- <https://www.bps.org.uk/news/division-clinical-psychologys-faculty-people-intellectual-disabilities-responds-tw-vs>  Jason suggested that other professional groups may want to respond this too  There are concerns regarding what happens to those people who have cognitive impairments and their additional risk/ intersectionality issues especially if they are not deemed eligible for specialist LD services.  He also asked whether there was something to think about with the CQC in terms of their registration cause. **(see link below)**  <https://www.nottingham.ac.uk/research/beacons-of-excellence/rights-lab/resources/reports-and-briefings/2022/march/intersections-between-exploitation-and-cognitive-impairment.pdf> |
|  | **Kirsten Lamb - Health Services safety investigation report**  **Awaiting Slides**  Kirsten share the report below which was published in November 2023, the reference case was a man of 79 who had a mild learning disability (see slides below)  <https://www.hssib.org.uk/patient-safety-investigations/caring-for-adults-with-learning-disabilities-in-acute-hospitals/investigation-report/>    **Findings**   * Patients are often cared for by staff in acute hospitals with no training and learning disability. * There is no defined model for acute learning disability in nursing liaison services. * The hospital improvement standards and benchmarking is only being funded until the end of March 2024. * Care passports and alert flags are unreliable and about the known health inequities for this population. * There were recommendations around developing guidance about the learning disability liaison nursing role and also workforce guidance to acute trusts to continue the funding for the hospital standards and to develop guidance on the practical assessment of mental capacity * To develop the care passport process with and reliable flagging to cover learning disability status and reasonable adjustment needs   **Points Raised**   * Most acute learning disability liaison services are 9-5 Monday to Friday at the absolute maximum and are often reliant on one person. When that person is on leave, there is no learning disability liaison service, as has happened in this situation. * Can we rely on there being an adequate supply of trained learning disability nurses to be able to do this acute sector liaison work when the equivalent of registered nursing is not part of learning disability nursing training. * We now only have one learning disability nursing course in the East of England * There is discussion about general workforce training within acute trusts but there is nothing specific about the physical health medical workforce * No doctor at present has any training in the physical health needs of people with a learning disability. * Meeting the medical needs of adults with a learning disability certificate training program was RAG rated green. * We are currently struggling to recruit doctors to that program for the next cohort, having had 90 applicants for the 40 places last year. We are not getting that number of applicants this year. * Strike action that's been taking place all year. This is inhibiting for acute hospital trust doctors and people's outcomes in acute trust will not improve until we improve the medical training of doctors in working in acute hospitals. * There was talk about getting a new GMC role around neuro disability. * There is no discussion about trying to get a new GMC role about learning disability physicians. * There is no encouragement through CQC or through health education England, about trying to and review and evaluate the existing. * As far as she is aware we have three current learning disability physicians, one working in a mental health trust in Northern Ireland, one working in an acute hospital in London, and one working in Community learning disability services in Hull. There has not been any clear evaluation of those posts. * Oliver McGowan training will be useful but it will not cover these sorts of complex medical problems.   Prof Roy felt it is disappointing to learn that the recruitment for that the recruitments for this course is proving to be difficult.  **Questions/feedback**   1. ***Siobhan – felt it would it be helpful for a group of us to come together and really work out what exactly we need to do? We have got liaison nurses and we keep coming up with ideas, some of which are evaluated so are not and as someone working in the public health agency in Northern Ireland. It is difficult to identify what would be the absolute best thing to do.***   Prof Roy suggested extra time is devoted to this. Lucy will also need to be included in the discussion.   1. ***Viki – asked whether there is anything in terms of the QNLD for liaison nurses, or anything we could do proactively around what our expectations are around liaison through a QNLD type project. We know from the outcomes of LeDER how key that that role but there is nothing from ICBs about what the expectation is around commissioning and asked if there is anything we can do on that?***   Prof Roy feels it is a complex issue and we need to spend some time at a future meeting scoping it properly. Viki suggested this could be a conference agenda item. |
| **6.** | **Updates (11.40 -12.15)** |
|  | **Senate Conference - planning for 7th May 2024- all age all nations.**  Viki fedback that we had talked about the conference being a showcasing of some of the key priorities of the Senate for example things we want to give more attention to nationally though, because we do so such a large programme of work. She asked that member give consideration to the following   1. What are the areas we feel are priority areas to share and showcase at the conference. 2. Working Group Volunteers – Viki raised that she would like to get some people together who will form part of a small working group and will work alongside herself and Ashok to develop a proposal for. Viki is happy to pull this group together. Heather Hanna, Viv Cooper, Siobhan Rogan, Marie Lovell, Ashok Roy have agreed so far but we need more volunteers.   Marie agreed to volunteer to help but it at present it would have to be as a family member as Skills for Care are not being funded to do anything specifically about people with a learning disability. There are some proposals and she has suggested some of the work that ICB have led on in terms of trauma. A discussion has also taken place around some of the complex physical health work and the learning from LeDER Programme. |
|  | **Dave Gerrard - Health Improvement Pharmacy Lead/Learning Disability and Autism**  **NHS England- STOMP/STAMP focus on MindEd**  Dave shared his presentation and discussed the content with members.  **(See presentation below)**    Dave advised Carl has been working on a survey which he has spoken to members about in and ask that all members view the following link. He also requested this be shared more widely <https://www.engage.england.nhs.uk/survey/5711c69b/> to recruit interested parties to the HEE MindEd STAMP stakeholder group. The Focus Workshop will be held in late January 2024 and requires all stakeholders/ Experts in the field across the professions. Please send names by emails to Dave by 14th December 2023  Dave also asked members to look at the statistics contained in the slides (which we were not aware of).  Volunteers |
|  | **Workforce Update -** **Legiewicz-Preston – (to ask for presentation)**  Lucy provided an updated on the 6 core workforce objectives which maps back to the work that they do with what was formally Health Education England and their workforce training and Education Directorate what they are called now. The strategic business cases span across the two and this is how they have secured investment for them moving forward. This was completed for all 42 ICBs and they have received a submission back and thanked everybody who participated in the data collection.  In terms of Oliver McGowan Mandatory Training, Keith Russ is the Health and Care Act ensuring that the workforce is trained appropriate to their role and this will link in to Kirsten’s health services safety investigation. The key is that people are trained appropriately to their role, and that's links back to that employer duty. The priority at present is securing more investment for education and training and a lot of the work they are doing in partnership with workforce training and education is aligned to upskilling.  She also shared that her role will be moving into mental health and she will covering mental health and disability and autism from April 2024.  They are also developing a neurodevelopmental credential with Royal College of Psychiatrists and are looking at a neurodevelopmental qualification and linking to therapies in the children and young people so there is a psychological therapy for children and young people with autism and learning disability and the curriculum is being refreshed.  They are also looking at a newer developmental approach to that work, which will include learning disability, autism and ADHD and are defining the list of criteria that that covers the credential with the Royal College of Psychiatrists for pilot, hopefully.  **Questions/Feedback**   1. ***Jason had a question regarding therapist pathway for children and young people and asked why not make it all age? He will be the Clinical Director of the UCL Doctorate of Psychological Therapies in the New Year and stated that if there is an opportunity for it to be a lifelong pathway he would be very interested.*** 2. ***Martha raised in response to Jason's comments she feels there is much more momentum around all age pathways. One of the problems they see continuously within LD services is the emphasis ends up going back on adults. There are a lot of nuances that are quite different with children's LD services for psychological therapies. Families are at different stages to adjustment coming to terms with having a child with a learning disability and in some sense thinks the interventions are potentially different.***   Lucy shared the children's part has come from CAMHS in terms of the therapy work and that is part of the refresh. They are working with them to ensure it aligns for consistency. They will also being looking at a neurodevelopmental practitioner. She explained It is all in the curricula and is very early work. It is in progression but they are looking at the nuances in terms of making sure the specifics are not lost and they have the right people. She also stated that it also must be for all four Nations. |
|  | **Update re Autism : LD Position Statement** - **Martha Kaxton-Lane**  To be provided at the next meeting |
|  | **Update re QNLD - info to be recirculated** |
|  | **CQC – Ken Courtenay written feedback**  **Restrictive Practices**  This work continues led by Marie Cox. We are putting together guidance on acute behavioural disturbance (ABD) following cases reported to CQC of people being intubated in order to manager their behaviour. It does not only deal with intubation but with how managing people's behaviour prior to they being intubated in order to prevent it from happening.  **Epilepsy**  The working group is a collaboration between the Epilepsy Specialist Nursing Association (ESNA) and CQC to produce guidance for inspectors when inspecting services that people with epilepsy use. We hope to have it approved in the New Year.  **Self-assessment Framework**  The new Self-Assessment Framework is underway and staff are implementing it. It was delayed for many months but went live in November 2023.  **Specialist Advisors in LD&A**  I am very pleased that CQC has created a group of advisors with knowledge and experience of working with people with LD and autistic people. They will advise and support inspectors on their work in services and be a resource to the wider CQC on policy, registrations, and inspections. For me as the National Professional Advisor, it is a great support to have the group.  **ICTR/CETR**  CQC has gained the contract from NHSE for two years to oversee the management of ICTRS in England which is good news.  **Personnel**  The work in the LD&A Programme is led by Rebecca Bushell-Bauers as the director supported by Stefan Kallee as her deputy. |
|  | **Updates by Exception (12.15-12.30)**  **Heather Hanna - CAIDPN**  Concern raised about inpatient units closing for children with a LD and impact of this for children in the community and unsafe practices as a result. Recognition that inpatient provision has its place as long as of a high standard and only when absolutely necessary**.** |
|  | **Feedback from NHSE Regional** reps to be sent |
|  | **Feedback from Professions** to be sent |
|  | **Feedback from meetings attended on behalf of Senate.-** no update |
| **7.** | **Any Other Business** |
|  | **Future Agenda Topics**   * Multicultural STOMP - Hassan Mahmood * OT Occupational Rights - RCOT * BTS guidance and community acquired pneumonias - combined presentations. * CAIDPN update re inpatient settings for children * Long Term Segregation/ Solitary confinement discussion * Scottish Green Party ABA discussion   **Dates for future LD Professional Senate meetings:**  4th March 2024 9:00am -12:30pm  3rd June 2024 9:00am -12.30pm  2nd September 2024 9:00am -12.30pm  2nd December 2024 9:00am -12:30pm  **LD Senate Conference:**  May 7th 2024 |
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