# Minutes of the Health Education England, Intellectual Disabilities Programme Board, working across London, Kent Surrey and Sussex

Wednesday 17 January 2018 1100 - 1430 hrs The Charis Centre, West Green Drive, Crawley West Sussex RH117EL

Present		Organisation
Annie Henley-Ashton	AHA	Surrey County Council
Trish Griffin	TG	Kingston University
Emma Gupta	EG	Sussex Community NHS Foundation Trust
Sarah Haslam	SHA	Dartford and Gravesham NHS Trust
Sally Hyde	SH	East Kent Hospitals University NHS Foundation Trust
Karen Lawson	KL	The Huntercombe Group
George Matuska	GM	Health Education England (KSS)
Rhona Westrip	RW	Health Education England (KSS)
In Attendance		
Emily Newsom	EN	Health Education England (KSS)
Apologies		
Viki Baker	VB	Sussex Partnership NHS Trust
Chris Brenan	CB	Cartref Homes
Simon Cook	SC	Kent and Medway NHS and Social Care Partnership Trust
Mili Doshi	MD	Surrey and Sussex Healthcare NHS Trust
Dave Hearn	DH	Health Education England (KSS)
Nicki Fowler	NF	University of Greenwich
Sarah Jones	SJ	NHS Brighton and Hove CCG
Corinne Nikolova	CN	Sussex Community NHS Foundation Trust
Annamarie Pedrosa	AMP	The Regard Group
Sally Smith	SS	East Kent Hospitals NHS Foundation Trust

#### 1 Welcome, introductions and apologies

- · Listed as above
- RW welcomed all to the meeting and Board members were asked to introduce themselves.
- EG and TG were welcomed and introduced as new members.

### 2 Approval of draft minutes and Matters arising from the meeting held 11 September 2017

- The board agreed the minutes as an accurate record.
- · Actions were revisited with progress updates.
- Action 1: RW advised the board that it became apparent in September 2017 that the project wouldn't finish on time due to the breadth of the subject matter. It would present as Research rather than a Pilot Project as required. It was agreed that the Darzi Fellow Sarah Trute would join another sponsor, Dave Hearn with a NHS England project. The project that Sarah Trute began work on for the ID programme is therefore not being taken forward.
- GM advised the board that the Intellectual Disabilities Programme had put in another application for a Darzi Fellow for 2018. The project being 'working across London, Kent Surrey and





Sussex, with TCP'S and STP'S to bring ID to the STP agenda' with the aim being Transforming care should become business as usual.

### 3 Members updates/News Stories

- RW provided a verbal update for AMP, SJ, and CN
- (1) AMP has secured a new role with The Regard Group, a big company across England. They provide services for children and adults with learning disabilities and this ranges from day services, respite, residential homes and supported living. AMP is working in a residential home with 9 men and 1 lady and there is also a man who has moved out of the service into his own flat thus providing outreach too. 'It's early days but so far the home seems lovely, they are very person centred and it doesn't feel like a residential home at all it feels like their own home.' The board welcomed these positive comments and wish AMP success in her new role. She will continue as a board member.
- (2) SJ During August to October 2017, the Sussex TCP identified a significant number of people with a diagnosed LD and/or autism, occupying mental health beds and who meet eligibility criteria for the transforming care programme. As a result, the TCP doubled the number of people in its CCG inpatient bed cohort from 23 (Q1 2017) to 44 (Q3 2017). The TCP has subsequently entered formal recovery plan arrangements with NHS England and is taking positive and pro-active action to redress this situation
- (3) CN West Sussex Big Health Event 20 September 2017 went well and minutes to be circulated. The purpose of the event was to hear people's views about health care for individuals with learning difficulties and, in particular, about cancer screening and the importance of having checks. It is understood that people with LD are less likely to have health checks and this needs to be addresses and improvements made.
- (4) SH updated the board and identified the following areas of concern and requiring work
  - 1. PWLD who are older and facing end of life are facing unnecessary hospital admissions due to a lack of education and understanding of their conditions.
  - 2. Planning better for EOLC, joint working with GP's and families by overcoming the difficult conversations.
  - 3. Misconceptions and prejudice. SH spoke about PWID who were unable to spend their last months in familiar surroundings but had instead to stay in hospitals.
  - 4. Concerns that patients are on a Learning Disability Register with no evidence of LD and vice versus not on the LD Register when they should be. The responsibility of the annual health check is not always with the GP but Practice Manager.
  - 5. Younger woman becoming pregnant and lack of education amongst midwives concerning the ability to consent. Work currently taking place with Midwives.

Action: SH to share <a href="http://www.respectprocess.org.uk/">http://www.respectprocess.org.uk/</a>
Action: EN to share EOLC Programme Manager details.

Action: SH to share GP County Council Action Plan when available

- (5) AHA advised the board of the following updates:
  - AHA and colleagues are currently working on developing a Learning Development team structure. Half are identified under TCP and CCG joint work. The new team is positive news and comes in line with the TCP's. The team structure is likely to take a minimum of six months to be set up so as to identify individuals who will have use of this service. Upskilling and recruitment is required, as it has been recognised there





is a significant lack of skill in this area. AHA reported she has significant caseloads she is also working through.

- There has been an increase in inpatients within the CCG between 6-8 being, numbers being under 30 originally. This has made a significant impact on workloads.
- AHA attends the LD board run by the CCG and TC leads meeting on a regular basis.
- AHA currently 'buddying up' with Catherine Fisher a Transition Manager and Surrey County Council are involved in the Recruitment for Leader programme.
- Surrey County Council are developing a high needs service for ten spaces for people with challenging behaviour and Autism. A site has been secured set amongst 3 acres of land.

A short discussion followed regarding mental capacity and discharge. GM agreed to share recent documents on the topic.

Action: GM to share papers on Mental Health Act 37/41 (MH briefing and Letter) Action: Paper on MHA proposed updated (Review Discussion)

- (6) KL provided the board with a brief update:
- Cedar House is a low secure provider.
- A recent focus has been retention and recruitment of Nurses
- Cedar House has links with Greenwich University and 'the Trainee Nurse Associate Programme'. Interviews are taking place in February to recruit six people to start in April.
- 3 students work with the Open University with the 'grow Your Own Nurse' Programme.
- Clinical Assistants (often psychology students) have been in post for the last 12 months which has supported the nursing team with administration support.
- KL has been having monthly meetings with the Transforming Care teams and thirty-three patients have been identified for discharge in the next twelve months.
- KL noted that the discharge can be a lengthy process due to funding and the coordination of community teams for placements. GM also recognised that a cultural change is required within commissioning to support Workforce Planning.
- KL advised the board of the success of the Recovery College, (which ID board are supporting) four qualified peer trainers identified and a further six interested. Patients are able to co-train and they are busy rehearsing seminars and workshops.
  - (7) EG is a Consultant Community Paediatrician for Sussex Community NHS Foundation and introduced herself to the board, and gave an insight into the work she is involved with.
  - Her role interfaces with LD.
  - · Case by case basis.
  - A high percentage of her role as a clinician is the coordination of care,
  - Assisting parents to link with various agencies.
  - EG looks at how ID is recognised by professionals
  - There is a lack of take up of Annual Health Checks for children from Fourteen years onwards.
  - Interested in how do we support to have AHC often there is a gap for children with ID rather than those that show physical illnesses.
  - EG personal interest is in Children's Public Health, and childhood obesity and the link between ID and likelihood of being more overweight. Currently, there is no data gathered on this, therefore no service offered.
- 4 Highlight Report including TCP plans and STPS





 GM advised the board that following on from the email distributed in October it had been agreed that London would join KSS for Intellectual Disabilties for the first Twelve months from October 2017. The board were presented with this brief. The programme title is now Intellectual Disabilities Programme working across London, Kent, Surrey and Sussex.



LaSE ID Programme BRIEF DEC17 (3).pdf

 The board were advised of the upcoming CYP London events for forming an Adult and CYP Community of Practice. Taking place in January 2018, as well as the Special Schools events with between 90 and 150 providers present.



- Children and Young People and Autism are to become more of a focus moving forward.
- February will see the opportunity for more bids and GM anticipates 30 pilot projects as a result of the London COP launch.
- RW provided an update by exception on the following as part of the Highlight report:
- Since the last programme Board, GM and RW have had three meetings concerning pilot projects, whereby they meet the team, receive an update on the programme as a whole and give advice and guidance concerning the writing of the report and sharing tools.
- November GM and RW visited Optimacare. Where a project had been running about Picture
  Exchange Communication Systems. There was considerable output from this, leading to a change of
  culture. Residents were now able to communicate with staff, this has led to fewer staff being hurt and
  attacked and to the workplace becoming a place where PECs was being integrated throughout.
- December GM and RW visited East Kent Hospitals Trust where the programme had supported a
  project concerning PWLD. Two permanent roles have been produced as a result. One almost full
  time. One part-time. The whole recruitment process changed from not having to complete via NHS
  jobs to actually doing the work on the ward as part of the interview, including easy read versions.
  This has become culture changing.
- Early January GM and RW visited the University of Surrey International Care Ethics Observatory who have been working on End of Life Care (EOLC) for CYP and adults with LD and what good looks like? As a result, a toolkit and video have been produced. Key learning points have been the bringing together of palliative care and Intellectual Disabilities. A lack of confidence on both sides had also been recognised. This work is going to be published and there may be some more potential for Simulation work within this area.

Action: EN to share March 2018 NHS England TC conference details

https://www.evensi.uk/transforming-care-sharing-solutions-real-difference-hilton-hotel/240400086

Action: EN to share November presentation at the VODGE event <a href="http://prezi.com/s-qcj0hcruly/?utm\_campaign=share&utm\_medium=copy">http://prezi.com/s-qcj0hcruly/?utm\_campaign=share&utm\_medium=copy</a>

• GM informed the board of the current Simulation work being undertaken by (Maudsley Simulation) acute staff and LD actors at the Baked Bean Co. <a href="http://bakedbeancompany.com/">http://bakedbeancompany.com/</a> and the potential impacts of this training for ID.

Action: GM to share finding of simulation work when articles are published.





#### 5 Sarah Haslam (SH) Lunch and Learn

- SH gave a comprehensive presentation based on her work as RDN and Oral Health Practitioner Mouth Care Specialist Nurse and the Project: The Mouth Care of Adults with a Learning Disability in Darent Valley Hospital
- The project highlights the benefits of joint working with LD liaison Nurses and MC Nurse.
- The duration of the project was for a year until January 2018.
- Aims raising awareness to the patient, family and carers of the importance of mouth care on general health of patients with LD.
- The presentation provided explained how a personal treatment plan can be made for individual patients, allowing for reasonable adjustments and building confidence and self-awareness.



## 6 BILD Community of Practice BID and KSS CoP extension request – This was covered in Agenda item 7

#### 7 Bids Re KSS

- Eight Bid proposals had been received in total, with a deadline 17 November 2017.
- Bids were bought up electronically and also paper copies with amendments were provided.
- The funding aims to improve healthcare of people with ID in the region by the education and training of staff.
- The attached template and criteria were required for submission:



RequestforfundIDK SSOct2017.docx

- The following Bids were bought to the board for approval and recommendation;
- (1) Sussex Partnership NHS Foundation Trust, Lead Proposer Viki Baker, Executive Sponsor, Simone Button

**Title:** One-day experiential training provided by the Family Planning Association to LD nurses across the LD service (up to 24), covering: 'LD, sex, law and policy'.

The board declined funding for this on the basis that this was a one off training intervention, and learning materials would be unable to share freely.

• (2) Sussex Partnership NHS Foundation Trust, Lead Proposer Karin Fuchs, Executive Sponsor Rick Fraser

The board requested responses to the below questions to be able to make a final decision:



- Could you provide some more information specifically surrounding the expected outcomes concerning each tier?
- Could we have some information on the key standards that are going to be audited?
- What are the overall numbers of staff that this training is likely to be available to?
- (3) Avenues South East, Lead Proposer, Sarah Kean, Executive Sponsor, Jo Land

**Title:** A Bridge to Vision, Identifying Sight Loss – Creating Opportunity.

The board asked for feedback on how eLearning is to be evaluated.

• (4) Surrey County Council, Lead Proposer, Thomas Moore, Executive Sponsor, Brian Mayers

Title: Surrey PBS Coaches

The board requested more information about how the impact on service and staff development will evaluated.

• **(5) The Huntercombe Group,** Lead Proposer, Emma Harrison, Executive Sponsor, Valerie Michie

**Title:** Enhancement of the Positive Behavioural Support culture within a secure hospital for people with learning disabilities and autism to improve patient outcomes and aid transitions into less restrictive environments.

The board asked for more information about the evaluation of the intervention. In particular, to include separate staff groups. For instance, how will the impact of training a gardener be measured with regards to patients and the service?

• **(6**) Sussex Partnership NHS Foundation Trust Lead Proposer, Esther Wilcox , Executive Sponsor, Dr Rick Fraser

**Title:** Developing staff skills to work with effectively with families to support the delivery of the transforming care agenda in Sussex.

 (7), Real Insight and Hart Consultancy Lead Proposer, Susan Hart, Executive Sponsor, Susan Hart

**Title:** Developing staff skills to work with effectively with families to support the delivery of the transforming care agenda in Sussex.

The board requested further details on the following:

"It's the non-specialist services that are commissioned within the CCG region but that have contact with this group of individuals that we are interested in regarding this scoping – i.e. including charity, hospices, even police and fire brigade etc. if you felt appropriate, and then following that information concerning how these very different organisations would be scoped. Anything following the scoping should not be included in this proposal as we haven't yet got the evidence that this work is required, so can't fund it at the present time."



Action: RW to respond to bid applications asking for further details as the board requested. Responses to be returned by the 1<sup>st</sup> February 2018.

• (8), BILD

Two bids have been agreed by the board

- 1. Agreement to extend the KSS community of Practice (agreed in meeting 170118)
- 2. London Stakeholder event agreed (previously signed off by the board via email)

#### 8 AOB

- GM shared certificates of appreciation with the group.
- These went to:

East Kent Hospitals University NHS Foundation Trust 'Employing People with Learning Disabilities'; Heike Guildford, The Coaching Nurse 'Staff Retention and Recruitment Programme'; Foundation for PWLD 'User Voice'

These projects were funded by HEE KSS ID board and have been successfully completed.

- ICE EOLC toolkit and video freely available.
- LSBU EN completed 'understanding ID' online learning.
- The next meeting will spend an hour using open space to explore how the board might work differently.

#### Reminder of actions:

Action: SH to share <a href="http://www.respectprocess.org.uk/">http://www.respectprocess.org.uk/</a> Complete Action: EN to share EOLC Programme Manager details. Complete Action: SH to share GP County Council Action Plan when available

Action: GM to share papers on Mental Health Act 37/41 (MH briefing and Letter) Complete

Action: Paper on MHA proposed updated (Review Discussion) Complete Action: EN to share March 2018 NHS England TC conference details

https://www.evensi.uk/transforming-care-sharing-solutions-real-difference-hilton-

hotel/240400086

Action: EN to share November presentation at the VODGE event <a href="http://prezi.com/s-">http://prezi.com/s-</a>

qcj0hcruly/?utm\_campaign=share&utm\_medium=copy

Action: GM to share finding of simulation work when articles are published.

Action: RW to respond to bid applications asking for further details as the board requested.

Responses to be returned by the 1st February 2018. Complete

Date and time of next meetings: Wednesday 17<sup>th</sup> January 1100- 1430 2018, Wednesday 25<sup>th</sup> April 2018, Wednesday 18<sup>th</sup> July 2018 and Wednesday 17<sup>th</sup> October 2018. Venue: Charis Centre Crawley, details to follow



