

# Kent, Surrey and Sussex Learning Disability Community of Practice

# Sustaining our Community Conference Evaluation

21 June 2018



## We are a Community of Practice working toward the eradication of health inequalities for individuals who have a learning disability

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#### **About KSSCOP**

The Kent, Surrey and Sussex Learning Disability Community of Practice was developed from Kent and Medway Learning Disability Community of Practice in 2016. The CoP is a group set up by local people who care about people with learning disabilities experiencing good health and wellbeing, and good health services.

The origins of this venture were spearheaded by Canterbury Christchurch University, East Kent Hospitals Universities NHS Foundation Trust and the English Centre for Practice Development with support from local statutory and third sector organisations. This group has now grown to include many others that now play a crucial role in the sustainable development of the newly launched KSSLDCoP as it moves forward.

The Community of Practice works toward the eradication of health inequalities by supporting carers, care workers and all professionals to:

- be person centred
- provide the best quality care and support
- improve equality and access

'Sustaining our Community' is our third annual conference.

Health Education England working across Kent, Surrey and Sussex has provided the support for this work to be facilitated via BILD.

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Appendix 1 - Delegate feedback on the whole event

### 1. Easy read summary of the conference



On 21 June 2018 the Kent, Surrey and Sussex Learning Disability Community of Practice held it's conference.

The conference was called: Sustaining Our Community.

Sustaining means supporting something to try to improve it, make it better.



Lots of people came together, people with learning disabilities, their families, friends and people they work with. We had a great day sharing ideas, building the Community of Practice (CoP).

The Community of Practice want to do the right thing for people with learning disabilities and make peoples' lives the best they can be.



We used colours and easy read signs for everyone to make their way around the conference.



We had a chance for everyone to present, including some great work from our co chair Andrew Walker of 'Stay up Late', Jim Blair of BILD and other people from around Kent, Surrey and Sussex.





On the day, we asked people to use social media to 'spread the word' about the great work we were producing, and this was another way for people to connect with one another.



We asked everyone to share ideas on how we can keep the Community of Practice going, thinking about how it might be paid for in the future and how best to keep the community moving forwards in the right direction.



We made a film with lots of comments, chats and interviews from people who came to the conference.

## 2. The conference planning and preparation process

The organisation of the conference programme was led by Tom Evans, BILD's PBS Development Manager, Tom looked at:

- theme of the event
- aims and preferred outcomes
- target audience
- identifying potential speakers
- structure of the day, timings of workshops
- venue, in terms of accessibility, room space, delegate capacities, equipment and provision of refreshments

The final programme and flyer were created based on the above discussions. Tom made contact and briefed the potential speakers and Liz (BILD events manager) then liaised with them around the logistics of getting to the venue and arranging what materials or equipment they required.

#### **Delegate bookings**

The event was promoted through all the identified KSS social media and networks and delegates were provided with a booking form on the flyer to secure a place. 108 delegates booked and in total 88 delegates attended on the day.

#### On the day

The day was a huge success, there was a positive atmosphere and the joint working, networking and knowledge sharing was tangible. There was a range of informative, diverse workshops for delegates to choose from, they attended two in the morning and two in the afternoon. Delegates were required to choose which workshops they wanted to attend and this was a tough choice due to the rich, valuable range of people presenting and the areas being explored and discussed.

Fortunately we were able to let people know that some of the workshops were being filmed, so if there was a 'clash' there was an opportunity to catch the session later on.

The topics covered on the day included 'challenging health inequalities, evaluation of mental health promotion, STORM - resisting stigma and enhancing wellbeing and

accessing healthcare for people with learning disabilities who display behaviour described as challenging.

The variety of areas discussed really enriched the experiences of the audience. Active, lively discussions and debates were taking place. Individuals from a range of personal and professional backgrounds were able to share ideas and resources and come together to expand their knowledge.

During the event we stopped to chat to delegates to find out what was inspiring and stimulating them about the event and discussed what the CoP meant to them:

"I enjoyed it very much, it's nice to do that"

"Someone asked me a guestion today that I'd not thought of, so we can take that away to others in the project and learn more"

"In a short day I've come away with so much information and my head is buzzing with ideas. Why didn't I know about this before?"

"It's important to be engaging, sharing together to get it right..."

"Because this is a health initiative it's about getting that link between health and social care better integrated"

There was a selection of market stalls provided by a range of organisations, delegates were able to visit these during refreshment breaks, allowing more opportunity for networking and information sharing. Attendees even made the most of the opportunity to network during the refreshment breaks and during lunch.

#### What did we learn for the next event?

Some feedback was received in relation to the delegate packs and the colour coded system, next year we may look at using a different identifier.

It would be really useful to provide people with the relevant hash tags, twitter handles and any other relevant information at the beginning of the event to ensure the social media profile is raised throughout the event.

It was suggested that when delegates sign up to attend they are able to choose their workshops then.

Better identification of BILD staff to enable delegates to find them for help or support during the event.

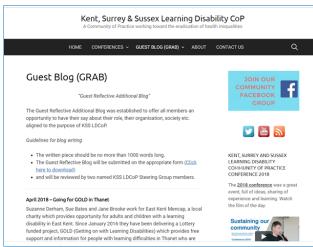
Encourage more attendance, participation and involvement from people with learning disabilities.

### 3. Conference promotion

In order to promote the conference, we produced a number of pre-conference emails for KSS members to generate conference delegate bookings as well as applications for stalls and posters. We also contacted the organisations who had set up stalls in 2017 to offer them the opportunity to exhibit again.

We also promoted the conference on the KSS and BILD social media channels and the KSS blog. A poster for the conference was commissioned which added to the profile. 108 people registered for the conference.





## 4. Sustaining Our Community Conference - the day

During the build up to the event there was a lot of awareness raised via Twitter and BILD's Facebook page, the social media focus was twofold - reminding people of the conference and also from delegates who were attending to present raising awareness, expressing their anticipation and excitement for the event.

It was important that potential delegates were aware this was a free event, this ensures the event can be as inclusive as possible.



Coverage on social media platforms included details on the variety of topics that would be covered during the day, and indeed during the day there was a prominent link to the opportunity to catch the live streams and details were provided via Facebook and Twitter so those unable to attend could be involved in some way.

The final expected figures of attendance based on the Eventbrite registration was 108, we anticipated some of these delegates may not attend and some additional delegates not on the Eventbrite list would attend. In total the confirmed number in attendance was 88.

#### Attendance and a fully engaged audience

The number of delegates who attended on the day was slightly less than originally anticipated, despite this the day went ahead with a real energy, all the participants were engaged and on board with contributing fully and they had a real passion for bringing the Community of Practice (CoP) to the next stage.

The feeling of momentum gathering was palpable throughout the day, every delegate and speaker attending had a shared enthusiasm for the progress being made and professional networks that were being developed as part of the CoP.

The core foundations of the CoP were taking place in every session, every discussion and even during the lunch break!

It was evident every member was passionate about the key principles of:

#### Improving equality and access

"If we want people to live in the community, how do we ensure community based staff have the learning in the health tasks they might need to perform?"

"If something like this didn't exist in the fullness of time skills would be forgotten, people would be set to one side as they were in years gone by"

#### Being person centred

"My dream is for people with learning disabilities not to be cutted, let them have the support they want and live the life they want"

"These are guys representing the whole service that is such an ACHIEVEMENT, it demonstrates to other services they can all do it, it is possible"

"Any disabilities or any illnesses doesn't stop you in life, keep pushing through and get through it"

#### Providing best quality care and support

"When we all work on the same level we can help each other more. We don't need to do more, we just need to share what we've got"

"I was in a workshop being delivered by a LD liaison nurse and she spoke very clearly about the need for education and training for the workforce to happen from the beginning and be embedded"







### **Sustaining Our Community**

## The Kent, Surrey and Sussex Learning Disability Community of Practice Annual Conference

21st June 2018 - The Charis Centre, Crawley, Surrey

#### **Programme**



9.30 am Registration and refreshments





Andrew Walker, Expert by experience and Jim Blair, Great Ormond Street Hospital

10.15 am Update on KSSCoP development, including launch of Facebook group Tom Evans, BILD and Clare Leahey

10.30 am Workshops (Choice of 7)

- 1. Development and implementation of Profound and Multiple
  Learning Disability Core and Essential Service Standards Michael
  Fullerton and Thomas Doukas, Care Management Group
- 2. Ways of communicating and reassuring people with learning disabilities to feel free to speak, including in relation to healthcare Bob Parsons, CWGSY



- 3. Overcoming the challenges in administering emergency epilepsy medication and assessing administration competency Jenny Spaull, Southdown Housing Association
- 4. Evaluation of mental health promotion groups and the views of people with learning disabilities who attended the groups Peter Woodward, University of Greenwich
- 5. 'It takes 2' project supporting people with learning disabilities to get more involved in their communities and have equality of access Martin Chittell, The Avenues Group
- Challenging health inequalities: the need for reasonable adjustments to deliver health care for people with learning disabilities

   Jim Blair, Great Ormond Street Hospital
- 7. Empowering recovery college peer trainers with intellectual disabilities to take up strategic positions in promoting mental and physical health Susan Hart, Nash Momori, The Huntercombe Group



#### 11.20 am Refreshment break

#### 11.50 am Workshops (Choice of 6)

- 8. The role of LD liaison nurses in supporting patients with learning disabilities in an acute trust hospital Eloise Brett, Medway Foundation Trust
- 9. 'Standing up for myself' (STORM) for adults (16+) with mild to moderate learning disabilities, aimed at enhancing their capacity to manage and resist stigma and have a positive effect on their wellbeing Lisa Richardson, BILD Consultant



- 10. Evaluation of the work of consultant co-teachers with learning disabilities who monitor and develop the quality of learning disability education Cathy Bernal, Canterbury Christ Church University
- 11. Providing tailored input, that has an impact on practice, to services supporting men with learning disabilities who are deaf/blind Jenny Spaull, Southdown Housing
- 12. Accessing healthcare by people with learning disabilities who display behaviour described as challenging Viv Cooper, The Challenging Behaviour Foundation



#### 12.40 pm Lunch

#### 1.40 pm Workshops (Choice of 7)

- Development and implementation of Profound and Multiple Learning Disability Core and Essential Service Standards – Michael Fullerton and Thomas Doukas, Care Management Group
- 2. Ways of communicating and reassuring people with learning disabilities to feel free to speak, including in relation to healthcare Bob Parsons, CWGSY



- 3. Overcoming the challenges in administering emergency epilepsy medication and assessing administration competency Jenny Spaull, Southdown Housing Association
- 4. Evaluation of mental health promotion groups and the views of people with learning disabilities who attended the groups Peter Woodward, University of Greenwich
- 'It takes 2' project supporting people with learning disabilities to get more involved in their communities and have equality of access – Martin Chittell, The Avenues Group
- 13. Devising a PBS framework to support people to attend health Appointments Lynsey Way and David Miland, Surrey PBS Network
- 14. Review of the Positive Behaviour Support training for parents co-produced by a school, City Council and NHS Trust Matt Steeples and Rosie McRae, Sussex Partnership NHS Trust



#### 2.30 pm Refreshment break

#### 3.00 pm Workshops (Choice of 7)

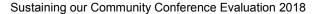
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- 14. Review of the Positive Behaviour Support training for parents coproduced by a school, City Council and NHS Trust – Matt Steeples and Rosie McRae, Sussex Partnership NHS Trust
- 15. Methods of promoting and facilitating access to healthcare carried out by Sussex Community Trust Daisy-Ann Hack, Sussex Community NHS Trust





4.00 pm Close



### 5. Sustaining our Community

The key questions for delegates to consider during the whole event was the next steps, how do we build upon the great practice already occurring and being demonstrated?

How do we, as members of the CoP, contribute to and sustain the desired shared outcomes of the community? How do we keep the current momentum of the CoP?

Two key questions were posed, and delegates were invited to leave their thoughts using post it notes, the questions were:

How do we sustain the CoP? Steering groups, involve education sector, 1. increase area?

(A quarter, 25% of those attending responded).

#### Steering group?

- 8 respondents were in favour of steering groups
- Suggested links and partnerships with other providers, for example, Mencap
- Involve stakeholders like CCG/CHC to provide funding

#### Include education sector?

- Yes, involve all, the response to this question was unanimous, respondents felt it's vital to include partners from education and SEN sector
- See blog from Bob Parsons: http://bit.ly/2uz7fFa

#### Increase geographical area?

- Don't extend area, as this lessens the 'community' feel of the CoP
- Yes, this enhances the wealth of knowledge
- This enables us to benefit from the direct experience of those living with and working within learning disability sector

#### **Potential barriers**

Only one respondent felt widening the geographical reach of the CoP would have a negative impact.

#### Comments

For steering groups, consider rotating members, this ensures there are a range of members with experiences to contribute and share experience within this context.

Communication: newsletter would be good (specific comment 'more upmarket newsletter').

#### Suggestions

Healthcare trusts to 'host' events?

#### 2. Sustaining KSSLDCOP membership and funding options

(A quarter, 25% of those attending responded).

#### Membership?

- 3 in favour of a membership
- 1 in favour of both fees/membership and sponsorship
- Involve stakeholders like CCG/CHC to provide funding

or

#### Sponsorship?

- Ethical sponsorship
- Try membership first then try sponsorships
- CSR?
- Who?
- Corporate sponsors
- Training providers



Specialist suppliers

#### **Potential barriers**

Access, funds, individual's financial circumstances, especially if people are in receipt of benefits.

#### **Comments**

Department of Health Education England should fund it as CoP is such a valuable resource.

#### **Suggestions**

Prize draw subscription? Social enterprise? Subsidised fee?











### 5a. Keeping the CoP going. Easy read



## How do we keep the community of practice (CoP) going?

Ideas were shared with us on the day.



#### **Steering group**

This is a group of members who volunteer to lead the activity of the CoP.



#### A partnership

This means a group of organisations who might join together to take the CoP forward.



#### **Keeping the CoP going**

Find money from other places?

Paid membership?

We could ask members to pay a small fee? But how much will it cost?

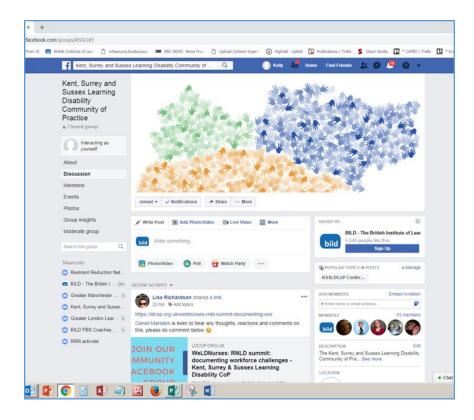


But, let's not make it too hard to be part of the CoP.

#### Plan of action on what next

Delegates were encouraged throughout the day to sign up for the closed Facebook group in order to stimulate the online forum for the group to utilise. The CoP now needs time to grow and to build on the excellent foundations already in place. The recruitment of a CoP network coordinator who was introduced on the day, Clare Leahy, will enable and support some of this, it is also the duty of the community members to continue their involvement and enthusiasm.

Spread the word, make colleagues, peers and friends aware of the vital contribution the KSSLDCOP makes. The way in which the community will engage and grow will vary, to include both online forums and face to face opportunities, developing and nurturing the role of community champions. All members of the CoP need to try to open themselves to engage with forums they may not currently be used to using. BILD can offer help and assistance, especially with the use of the closed Facebook group.



## 6a. What next? Easy read



Let's talk.



#### Facebook page

Please join our closed Facebook group, ask us if you need help with this.



#### Tell your friends

We want as many people as possible to join the group.



#### Keep in touch

We want to keep hearing from you so please stay in touch.



#### What do you want?

Keep us busy! Tell us what it is the CoP can do for you. What is happening in your life? Good or bad experiences that the Cop can help you with.

### 7. Responses to the day

#### Social media activity

It is fair to say the main vehicle for promoting the awareness of the event prior to the conference was largely via social media, this was also true throughout the event and in the few days following the event. Delegates and participants were engaged in tweeting their thoughts and feedback on the day.

#### Delegates' feedback

Delegates were asked their views on the event as a whole, see appendix 1.

Throughout the day delegates made the most of opportunities to engage with the members of the team from BILD to provide verbal feedback and make suggestions, including a very relevant question about meeting the needs of those who may be colour blind when using colours for the room orientation – all great feedback we can use to improve the experience for attendees.

#### End of the day conference video



The video can be viewed at:

https://vimeo.com/277263727

### 8. Appendices

## Appendix 1: Delegate feedback on the whole event

#### **About the Community of Practice**

What currently works well in supporting professional development for the LD workforce across Kent, Surrey and Sussex?

Yearly conference

Multiagency/family networking via Surrey PBS network and

Transforming care group

Good communication amongst professionals from all areas – sharing knowledge and experiences sharing case studies

Sharing positive ideas and good practice

Day like today, reinforces the reason why I do my job

Training conferences

Being able to access some of the presentations – powerful

Being able to access social media site from the website without

having to be involved with Facebook. It is good to see BILD doing something for members to see

Event like this where everyone meets

Joint training days

Sharing good practice

Partnership working

Conferences

**Forums** 

Peer support groups – formal and informal networks – Surrey PBS Network

I do not know yet

Good to hear about forums such as today

I haven't seen a lot of jobs online for LD nurses. Today has been good but it needs better advertisement

COP blog and emails (COP + HEKSS). Funding from Hekss

Networking opportunity, sharing ideas Varied workshops We have lots of great resources in our trust for CPD

## What kind of things could be provided that would improve this still further?

Increase networking between communities/health, social, ed performing/families with specific focus groups (and users of service) More than one conference in the year

Involving educators, carers as well as health professionals (the EHC plan includes all those sectors)

Accessible training

Breaking down barriers

Better understanding of conditions

Regular meetings to share ideas and good practices

More of these days – really informative

A certificate and evidence of attendance for the WMC

Changing the chairs in Lindhurst room – quite uncomfortable N/A

Making this broader. There are lots of pockets of good joint working and this needs to be broadened out

Community support

More participants with intellectual disabilities linking in with professional bodies

Maybe more links and updates with what is happening across the network

Planning addressing things from services info/perspective

Too low a profile in social care – needs much greater publicity eg neither 1, nor another provider, knew about local groups

More expert by experience involvement

The range of sessions was perfect!

Use of virtual learning environments

Better funding for simulated practice

FB group is a promoting initiative

More of the same

**CPD** 

Not sure

## What do you need from the online forum (closed Facebook group?)

Information about relevant event/conferences/courses

Good topics to exchange stories/ideas/explore barriers and creative means of breaking down barriers

Sharing experiences – new easy read material

Sharing ideas, experiences, info, advance knowledge of events, etc Sharing of best practice

Support and advice on helping those with LD accessing things

Space to share ideas/experience – up to date information

I am currently not on Facebook as I avoid it as a registered practice nurse

Info. Re: training events, innovations, good practice etc.

Sharing the learning and feedbacks

Initiative of good practice

Sorry not really interested in Facebook – but think for a lot of people it would be a good idea

Update, news, experience exchange, what's working elsewhere, new funding opportunities for LD and PBS initiatives

Not sure – linked to other good practice etc

Hearing from likeminded professionals, sharing and keeping up to date

Dates of events/activities for people with learning disabilities around early exchange of ideas and sharing of practice

Information sharing

Resources

Helpful links

Update

Shared easy read resources

#### How often do you want local or face-to-face forums?

Big annual event, but perhaps smaller networks on a more regular basis

Depends on focus and availability courtesy at least

Remove politics from support – we're all in this for the same reason As often as possible

Maybe 3 or 4 times per year

Monthly or bi-monthly

3 monthly

Ability to network and know what good practice is happening in the area

1-2x please

This is my first time

Quarterly

Quarterly

Even 3 maybe

Every few months - 3 or 4

3 x week

Bio, monthly

1 a year is fine

Quarterly

6 months - 12 months

1-2 a year

Local – bio yearly

#### What do you want the forums/meetings to be about?

Perhaps range of event/rolling programme, eg children with LD, palliative care

We support different types of need as range of topics can be board On topics that need more promotion new care pathways etc CPD opportunities, sharing knowledge, understanding others perceptions

Autism, mental health, behaviours of concern that may enlarge Different current topics

Mental health issues in PLD

Communication tools

Early intervention/support children and families CETR

MCA and DoLS children

Current topics cause issues

Evidenced based research issues

For family to be added

Different topics – good practice

Collaborative working and sharing learning

Examples of good practice

Opportunity to share good practice, resources and catch up with peers and any updates

What everyone is doing their challenges and solutions, and strategy tips

My role is to find out ways of increasing uptake of screening and immunisation in LD population across Surrey and Sussex

Local initiatives, sharing

Progress in services for people with learning disabilities

Practice development for patients with LDs

Developments

Good practice

#### Any other comments?

Enjoyed event

It is a wonderful day

Thank you, great event very much enjoyed it

Can't really comment on workshops and was delivery – but thought STORM sounded great

None

#### About the event

## Do the range of workshops and speakers reflect your professional interests?

Yes, good range of workshops

Yes

Yes

Yes

Yes, they were great, I wanted to attend so many

Fab! So many I wish I could have attended them all

Yes

Positive behaviour support

Health inequalities

Yes

Yes, broad range of speakers and topics covered

Yes

Some of them

Yes

Yes definitely!

Pretty much perhaps would have liked to hear more about initiatives in healthcare education

Yes

Yes very much so

Yes

#### What topics would you like to see discussed at future events?

Children's LD services

Smaller themes but we require different focus. Be good to share examples of local partnership working

Not sure, shall have a think!!!

More connection with education

Raising resilience for self-advocates and their families

Empowering those with LD and their families

Training and support for staff and volunteers

Most of the topic discussed today

Forensic issues in people with LD living in the community

Lack of legal framework around such people

Similar

Maybe a few more in depth case studies

Making presentations of learning disability individuals

Screening and immunisation – how to increase uptake

What measures are available for 18+ as they transition

All covered!

Upskilling the genic healthcare workforce

Positive behaviour support

Communication and sensory needs

Mental health

Feedback from services about effective models

Autism

**PBS** 

Communication – non verbal

Sensory

**PMLD** 

Transforming care

**CETRs** 

Behaviour and SALT

## Did you like the format of fewer presentations and more workshops?

Yes, although a mixture would be good

Yes, however, a lot of workshops – needed more attendees. Share more people didn't attend given it was a free event

Yes

Yes, good format

Over two days and maybe a mixed of presentations

Would like 2 days to be able to explore more workshops

Yes

Yes

Yep, most definitely

No thank you, I prefer fewer presentations over workshops

Yes

Yes, although could shorten lunch and breaks and have 1 more big

group speaker?

Prefer a mix

Yes this helped keep my interest going

Perfect!

Yes

Yes

Yes - nothing to compare to but if involved well

Yes

#### What would you like us to improve for next year's conference?

More live streaming

Found it difficult to choose with so many workshops at same time Need far more presentation beforehand to increase members attending

More people to network a little more

Nearer to Kent!

More time to get to make workshops

2 days!

Assumption include parents

Hot food instead

Nothing springs to mind, great, thank you

Signposting for the issues of workshops

More advance notice – with detail of programme earlier

Directions to car parking

Nothing it was perfect

More advertisement earlier on!

Get more people with LDs involved

Maybe the same

## What is the most important thing you have learnt at this year's event?

PBS approach to accessing healthcare was very valuable

PMLD standards was not aware of these before

Need far more of this

Everything was very useful. Enjoyed challenging behaviour foundation

Networking opportunities of getting to hear other practitioner's experiences

That there is amazing great work going on around the country and involving the self-advocates

That we are all striving for the same outcome and support is

available for those working in the sector

How to plan and co-ordinate with professional when my daughter is sick

Great opportunity to network

Reassurance of consistent message to look at health reason for change in behaviour

Information of resources

That these are a lot of approaching and tips that work, only when people shared them

Brain in hand! Really useful sounding apt

Increase in LD nurses in acute settings

As new to role the day as a whole has been of great interest Positive behaviour support for people with learning disabilities from both point of views service users + health care professionals! Unsure

Useful contacts

Mental health promotion info

**Enjoyed stories** 

Networking





