

Kent, Surrey & Sussex
Learning Disability
Community of Practice

Kent, Surrey and Sussex Learning Disability Community of Practice

Building our Community Conference Evaluation



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 launch 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

Building Our Community is our second annual conference. Read last year's evaluation here: <http://bit.ly/2gEVXba>

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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1. Easy read summary



On 15 June 2017 the Kent, Surrey and Sussex learning disability community of practice held it's conference.

The conference was called: Building Our Community.



It brought people with learning disabilities and family members, and people who provide support, together so they could talk about what to do to make the community work well in future.

The aim was to get things right for people with learning disabilities.



The conference had speakers and workshops on important subjects.

One workshop was about stopping the use of medication on people with learning disabilities when it isn't needed.



To make sure that people with learning disabilities could be involved as much as possible, all the conference materials were in easy read only—for the first time

And people with learning disabilities were invited to be speakers and run workshops.



On the day many people used Twitter to talk about the speakers, workshops and the two people who ran the day— Andrew Walker of Stay Up Late, and Sally Warren of Paradigm.



There was a consultation—asking people to say what they thought and wanted—about what the community should do in future.

This was done in small groups so everyone could have a say.



A film was made of the day showing what went on and who took part.

This was shown at the end of the conference and everyone really liked it.



At the end everyone wrote down what they thought about the day - these were stuck on the 'KSS Tree'.

People's thoughts : 'Inspiring and interesting!', 'Great chance to share good practice', and "Exciting, inspiring, and fun'.

Everyone had their photo taken around the tree!

2. The conference planning and preparation process

The organisation of the conference programme was mainly led by Tom Evans, BILD's PBS Development Manager, this took the form of a series of conference calls with the team to ascertain:

- Overarching theme of the event
- Aims and outcomes
- Target audience
- Identify potential speakers
- Structure of the day and potential timings
- Venue in terms of room space, delegate capacities, equipment and refreshment provision

The final programme and flyer were developed based on those discussions. Tom initially contacted and briefed the speakers and Liz (BILD Events Manager) then liaised with them around logistics of getting to the venue and providing presentations and materials for the delegate packs.

Delegate bookings

The event was promoted through all the identified KSS networks and social media platforms and delegates were invited to complete and return the booking form on the flyer to secure a place. This resulted in 150 delegate bookings.

On the day

The day was a mixture of keynote presentations and workshops. Delegates were able to sign up to their chosen workshops on the day. There were also a number of market stalls provided by organisations that delegates were able to visit during the refreshment breaks. The whole event was well attended with approx. 120 delegates attending.

What we could do differently next time

Whilst the whole event was a great success and well attended, there are a few things that would need to be addressed for the event next year:

- Ideally planning needs to start 6 months in advance of the event

- Smaller conference planning group – 2 or 3 people max. reporting back to wider team
- Venue – needs to be in a more central location for each of the 3 counties, with good access from both public transport and motorway networks
- Better catering facilities
- Venue needs to be bigger to enable more flexibility when developing the programme i.e. more breakout rooms, bigger area for exhibitions/market stalls

3. Conference promotion

In order to promote the conference, three pre-conference emailings were produced using the Mail Chimp account to generate conference delegate bookings as well as applications for stalls and posters. The majority of workshops, stalls and posters were recruited by directly contacting the leads of projects funded by HEE; a smaller number came from the mailings. Abstracts were reviewed and workshops and stalls allocated.



One mailing was produced from the BILD email system which was sent to the 400+ contacts in the area. The data shows that 32 people clicked on the link to download the conference booking form from this mailing.

A poster for the conference was commissioned which added to the profile and messaging around the event as well as a Twitter card to use in social media promotions. Easy read versions of the conference programme, the consultation document, the workshop titles and abstracts were also commissioned.

150 people registered for the conference, a waiting list was established as this was the maximum possible and 125 people attended.

4. Building Our Community Conference—The day

The response to the conference promotional materials and ‘blitz’ of promotional social media activity pre-conference had created a real ‘buzz’ of anticipation and an expectation that the day would go well. We’d seen lots of messages on social media from delegates and those running workshops saying how much they were looking forward to it.



A 150 place limit had been set on the numbers able to book, and this figure was reached a fortnight before the day of the conference. Knowing that there is usually a significant ‘no show’ for pre-booked but free conferences places, a waiting list had been established.

Social media messages were distributed asking those who found that they weren’t going to be able to attend to let the organisers know so those on the waiting list could be approached to fill the spaces.

Nevertheless, the day arrived with a nagging question – would it turn out alright on the day?

A great attendance and an enthusiastic audience

It turned out that we needn’t have been worried, the percentage who’d booked and failed to turn up was low and the end result was well over 120 delegates in the hall on the day.



As important as the numbers, those who came showed a real enthusiasm about both the day and the purpose of the Community of Practice (COP). There appeared to be a real excitement and willingness to both learn, share, and contribute to taking the COP on to the next stage.

All the workshops were well attended, the keynote speakers went down really well. The conference chairs, Sally Warren of Paradigm and Andrew Walker of the Stay Up Late campaign were very well received and helped the day move on with even more spirit and energy.



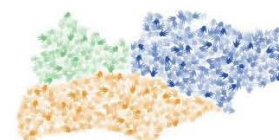
The consultation session on how best to take the COP forward, led by Tom Evans, was particularly well received. The final session where delegates were invited to place their thoughts about the day on the 'Build Our Community Tree', went down really well.

The noticeable 'buzz' about the day is clear to see in the end of conference video produced during the day. This enthusiasm and energy bodes well for the future of the Community of Practice.

Building our Community

Kent, Surrey and Sussex Learning Disability Community of Practice Conference 2017

Thursday 15 June 2017, 9.00am– 4.00pm, The Charis Centre, Crawley, Surrey



Kent, Surrey & Sussex
Learning Disability
Community of Practice

Programme



9.00 Registration and Refreshments

9:30 **Welcome**

Andrew Walker, Stay Up Late, and Sally Warren, Paradigm

9:45 **Building the community of practice to enable best quality of care and shared values: person centredness and equality of access**

Kim Manley, England Centre for Practice Development



10.15 **Planning My Support**

Andrew Walker, Stay Up Late

10.30 **Workshops:** Choice of 1 - 4



1. Good Eye Care - What you need to know

Aylee Richmond and Grace McGill, SeeAbility



2. Learning Disability Pledge - Employing More People with a Learning Disability

Twyla Mart, Kelly Wells, East Kent Hospitals NHS Foundation Trust and Mitch Mitchell, Kent Supported Employment



3. Anticipatory Care Calendar - Introducing Innovation - Peaks and Pitfalls

Sue Marsden, Kent Community NHS Foundation Trust



4. Reviewing Health Equalities and Data Intelligence in Learning Disabilities

Megan Hare and Shane Webber, Kent Community NHS Foundation Trust





11.10 Break

11.30 **Stopping Over Medication of People with Learning Disabilities, Autism or both**

Carl Shaw, STOMP



11.45 **Community Consultation**

Tom Evans, BILD

12:30 **Workshops:** Choice of 1 - 4



1. STOMP (Stopping The Over-Medication of People with a learning disability, autism or both) for social care providers
Jill Parker and Carl Shaw, VODG/NHS England



2. Workforce development for people with intellectual disabilities from the perspective of people with intellectual disabilities

Christine Burke, Foundation for People with Learning Disabilities



3. Positive Behaviour Support Workforce Training Project
Shane Carroll and Sarah Kean, The Avenues Trust Group



4. What difference does MOOC make? Lessons on working with open access learning materials to challenge and inform people about working with families with intellectual disability in different contexts of care.

Sally Hardy, London South Bank University



1.10 Lunch

2:10 **Workshops:** Choice of 1 – 4



1. STOMP (Stopping The Over-Medication of People with a learning disability, autism or both) for health care providers
Jill Parker and Carl Shaw, VODG/NHS England



2. The process of supporting individuals with Intellectual Disabilities to engage in co-production and co-delivery of Recovery College

Susan Hart, The Huntercombe Group & Nash Momori, Real Insight Consultancy





3. Advanced Care Planning at the End of Life: Views of Young People with Intellectual Disabilities

Ann Gallagher, University of Surrey



4. Evaluating the effectiveness of epilepsy training in services

Sunil Rodrigo, Yourhealthcare.org



2.50 Break



3.10 Film of the conference, summary of the consultation and next steps

Tom Evans, BILD

3.30 Evaluation of Conference

Andrew Walker, Stay Up Late and Sally Warren, Paradigm

3.50 Closing comments.

Andrew Walker, Stay Up Late and Sally Warren, Paradigm



4.00 Finish

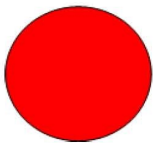
At the time of production this programme was deemed to be correct. However, we reserve the right to alter or cancel any part of the programme due to unforeseen circumstances



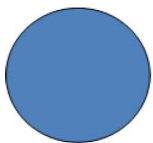


Morning Workshops

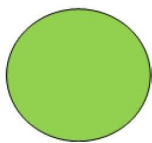
starting at 10.30



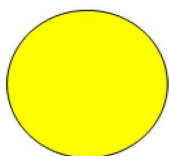
1. **Looking after your eyes.** By Aylee Richmond and Grace McGill.



2. **Our promise to give jobs to people with learning disabilities.** By Twyla Mart, Kelly Wells David Stenning and Mitch Mitchell



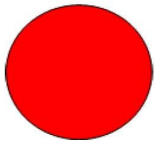
3. **Keeping a check on your health - how well it works.** By Sue Marsden.



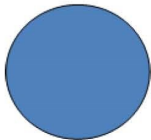
4. **Are you getting a fair chance at good health?**
By Megan Hare and Shane Webber.



Workshops starting at 12.30



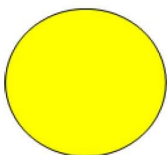
1. **STOMP - stopping people with learning disabilities or autism having to take too much medication.** (For staff in services, families and those being supported) By Jill Parker and Carl Shaw.



2. **What people with learning disabilities say staff need to be good at.** By Christine Burke.



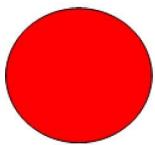
3. **Training staff to support people to behave in positive ways.** By Shane Carroll and Sarah Kean.



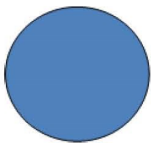
4. **Using internet courses for staff training.** By Sally Hardy.



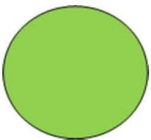
Afternoon Workshops starting at 2.10



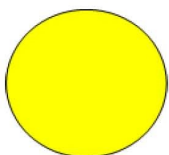
1. **STOMP - stopping people with learning disabilities or autism having to take too much medication.** (For health care providers). By Jill Parker and Carl Shaw.



2. **Setting up a recovery college with people with learning disabilities.** Learn how to deal with your health problems yourself. By Susan Hart and Nash Momori.



3. **Planning for when you die. What young people with learning disabilities think.** By Ann Gallagher.



4. **How good is our training on epilepsy?** By Sunil Rodrigo.

5. Building Our Community – the consultation



A key part of the conference was to consult with community members around the future development of the community. Suggestions discussed previously with key stakeholders around ways to help the community to develop and to become self-sustainable included the use of social media and online events such as webinars, having champions to lead on specific areas and the facilitation of local meetings taking place between annual conferences.

Prior to the conference the format for the consultation (and indeed the overall programme of the conference) was agreed by the members of the wider evaluation/discussion group; these are George Matuska, Rhona Westrip, Daniel Marsden, Simbarashe Masomera, Alan Rosenbach, Sally Hardy, Becky Quin, Patricia Griffin, Carrie Jackson, Cathy Bernal, Rags Subramanian, Claire Fields, Andy Fitton, Julian Seal, Anton French, Niki Fowler and Andy Nazarjuk. This format was that delegates, in groups of 10 sitting around tables, would be guided by a table facilitator in discussing a set of pre-prepared questions. The questions proposed were informed by the suggested areas for community development above and approved by the wider evaluation/discussion group, many of whom also agreed to be table facilitators.

Consultation questions were grouped around four themes:

Local meetings:

- Would you like to come to local meetings to share ideas and work together on topics that interest you to support the work of the Community of Practice?
- What topics would you like the meetings to be about?
- Any other suggestions about local meetings?

Champions:

- Would you like there to be people who take a lead in specific areas of interest?
- What areas of interest should there be a champion in?
- Are you interested in being a champion or do you know someone who would be?
- Any other suggestions about champions?

Online and social media options:

- As well as the blog, what else online would you like?
- Any other suggestions about online and social media?

Webinars:

- Would you like to listen to people talk about topics that interest you and ask them questions online?
- What topics would you like webinars on?
- Any other suggestions about webinars?



These questions were provided in easy-read versions for community members prior to the conference so that members unable to attend would have the opportunity to be consulted. At the conference all delegates had a copy of the easy-read questions and table facilitators recorded delegates responses to the questions on large sheets. The responses were quickly reviewed during the afternoon of the conference and a summary provided to delegates before the end of the conference.

6. Results of the consultation

Delegates overwhelmingly wanted local meetings. There were various ideas about potential purpose and agendas and ideas for ensuring their success and relevance.

Key themes around meetings purpose were:

- Sharing examples of good practice, case studies, avoiding duplication of work through sharing information and data
- Sharing information on good local services, events, training, how to access services (and also examples of where access is difficult and where service is not good)
- Opportunities for partnership working, networking and identifying contacts (including opportunities for engagement in research)

Key themes around the arrangement of meetings were:

- A mixture of attendees, including CoP members with LD (and ensuring information used is in easy read), also needing to include direct carers/contact staff
- Meetings being led by champions and people with LD and CoP members to set agendas
- Meetings/events with an invited speaker or specific theme and with time for questions and discussion
- Needing to 'target'/focus on contact with G.P.s (also a mention of M.P.s, policy, advocates)
- Needing to be accessible re public transport and timings



Delegates thought that having champions was a good idea. Some delegates had discussed the role of a champion and the potential issues and challenges of taking on the role and most listed potential areas that would benefit from having a champion. Delegates suggested that champions were needed in many areas.

The following areas suggested as needing a champion, related to the aims of the CoP, were proposed by a number of members:

- Publicising the need for baseline assessments for people with Downs Syndrome
- Healthcare education for people with LD including nutrition, exercise, health and well-being
- Improved healthcare for people with PMLD
- Improved healthcare for people with LD from ethnic minorities
- Improved healthcare for children and young people—working with schools etc. to promote good health
- Specific health conditions e.g. epilepsy, diabetes, dementia, mental health conditions
- Mouth care, eye care
- Relationships and sexuality
- Access to acute healthcare, including A & E (LD liaison nurses).
- Accessible healthcare information (including letters and the need for reasonable adjustments)
- Improving knowledge re LD for GPs
- Capacity/MCA in relation to health decisions
- Accessing health screening
- End of life care, joining together services/hospice/speech/OT etc.



In terms of online option there were various suggested formats including Yammer, a Facebook group, LinkedIn, Twitter, Pinterest, Instagram. The uses of these was also varied.

Suggestions included:

- Database of all members of CoP, local group contacts, list of experts, list of champions
- Forum – for specific subjects/discussion groups
- Podcasts on different topics

- Central resource ('knowledge hub') with members putting in practical tools
- Signposted links to resources e.g. papers, books
- Real stories about people
- Local meeting information, contact numbers/services/partnership boards
- Calendar of events/activities –updated regularly

There were a number of references to information needing to be easy read and that accessing online resources was tricky for some people.



There was less enthusiasm for webinars, but as this was the last set of questions in the consultation it may be that groups ran out of time, ideas or energy. Topics for webinars included people's experience of different services and the idea that webinars could be a safe place for people with LD to discuss ideas/ issues.

The majority of suggestions were around using webinars to disseminate information, for example when things are happening like services changing/moving, benefits changing/new things, local government policies, research, new projects and initiatives as for webcast of a meeting. Again there was reference to the need to consider people's ability/capacity to access webinars, that the quality of technology and accessibility may be an issue that being able to participate may be a problem including need space to listen to the webinars in the workplace.

Actions for the future



Local meetings

There was a clear interest in local meetings. As there wasn't agreement on specific agendas or formats it is proposed that local meetings are arranged to produce a standard outline agenda for the first meeting based on analysis of the consultation exercise. These can also look at holding meetings/events on specific themes; these can be guided by

suggestions made during the consultation exercise. It also seems sensible to plan local meetings with champions.

Tom Evans has linked up with the lead of Mencap's new health campaign ('Don't Miss Out') who was unable to attend the conference and we have agreed to co-host local meetings in January to publicise the work of the community and Mencap's campaign as both aim to ensure that people with learning disabilities have full access to healthcare.

Champions



Delegates who put themselves forward as potential champions are being contacted and discussions held with them around how they see the role of champion, what they may be able to do and what support they may need. These discussions are ongoing, but to date, that which individuals are able to offer is diverse. It seems sensible that asking champions to think about

and suggest what they are able to do, rather than by presenting them with a prescribed role, is sensible in terms of commitment and sustainability. However if an individual needs suggestions around what the role might look like we are able to make suggestions. One area where the need for a champion was suggested was acute settings liaison nurses. I have contacted a community member, not at the conference and she is considering how she can take this forward, likely to involve inviting me to speak at a regional network meeting of liaison nurses.

Online and social media options

Responses in relation to these will inform solutions being designed by BILD's IT consultant currently.

Webinars

We need to discuss the consultation feedback with key stakeholders before planning actions around webinars.

What didn't you like about today? (43 responses)

- The coffee! (5)
- Room too cold (10)
- Nothing (5)
- Queues for lunch and refreshments
- Time constraints
- No primary care
- Distance to travel/M20!

Anything else you'd like to say? (20 responses)

- Keep us working together and learning more. Thank you and well done.
- Hope we can harness the energy today to keep the cop sustainable
- Wonderfully informal and lots of good information
- Too many subjects with insufficient time to discuss and learn
- Could there be 'themed' events, eg, PLD and prison / SEN schools / annual health checks
- Very good! Hope to come back next year

End of day conference video

A video was made highlighting the excitement and activity during the day which was shown to delegates at the end of the day and used for post-conference social media activity.



This can be viewed on YouTube here: <http://bit.ly/2frh1kQ>

8. Appendices

Appendix 1: Consultation Questionnaire Results

Local meetings – the meetings will be about support and care for people with learning disabilities.

Do you want to come to local meetings to work with us?

Yes	No	Don't know
Unanimous		
To KSS plus separate KSS across the 3 regions – could be regional Depending on regularity networking, travel issues		Smaller agendas/make time for chat
4/4		
√		
How local is local? – half an hour – 1 hr is OK.		
3		
8		
1		

What do you want the meetings to be about?
<p>Improving healthcare inc private sector. More examples of good practice – case studies. Engagement in research. Ensuring delivery of NICE guidelines Avoid duplication of work through sharing information. Pooling data and sharing evidence base Ask group members with learning disabilities if they would like specific roles. eg leadership. Principles of easy-read etc. Explore links with DPGs.</p>
<p>Networking and fertilisation Specific speakers to be invited Knowledge and practice sharing Something around independence Make generalised Ask COP members to feed into agenda</p>
<p>Innovation – to introduce into practice Sharing information Best practice Networking- helpful later Partnership working Want opportunities and support to take innovations forward</p>
<p>Accessing health services – health checks/eye checks/ear checks/dental health Letting people know where there local GP/services are Let people know about where the District Partnership groups/meetings are happening and how to attend. Widening the attendees of meetings – fresh blood. Raising issues about lack of serviced/professionals/support</p>
<p>We need to target GP practices Have people with Id on Patient Participation Group Bottom up Start with GP practices. Put pressure on. Have people with Id training and accessing GP's. Local MPs need to be on board.</p>
<p>Looking at key issues – sharing ideas how to address best practice</p>

Frequency of meetings (are they useful/managers won't allow people to attend if don't see relevance
Maybe infrequent face to face with virtual meetings between
Responding to national changes – NMC changes to nursing training
Not meetings for meetings sake!
Where does stuff generated from meetings go?
What is done with it?
Information sent by email – forwarded/not read – who should attend the meeting?

Dotted meetings could become fragmented. Meetings could be more frequent, quarterly, larger participation.
Helps potential funding to draw best practice together.
Drawing awareness to the multi disciplines and resources and promoting the joined up working.
Capacity assumptions often made by clinicians to speak to carer/support rather than person. Often diagnostic overlay.
Must include people providing /directly supporting S.U's and their experiences/stories positive and negative.
To empower those supporting people to know what they need to know and be confident on what to say, what to do and where to go with it.

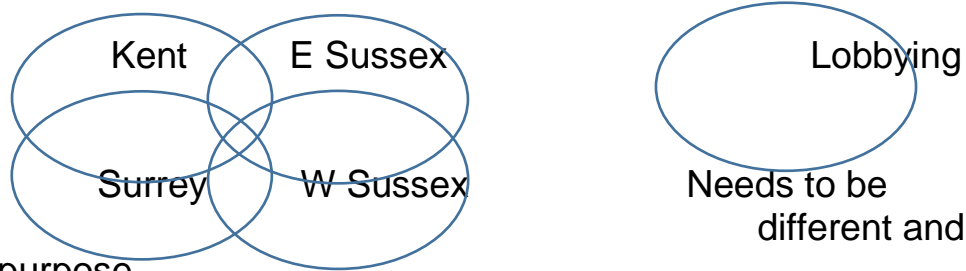
Agencies/facilities – Resource sharing
Building 'tool kits' – Resource packs
Sharing information not so locally biased
Personal experiences of pwld
Making sure not repeating 'work' already done
Champion with a person with a LD co-facilitating
Focussed meetings
Mixed groups
Developing good practice

Sharing ideas and best practice
Health care
Communication.
Person led support
Opportunity for pwld to participate and develop
Importance of joint groups
Accessible meetings
Public health issues – access
Relationships – joining/including existing forums

Sharing – grouping all meetings across – link in to COP.

What is working - Sharing
 Cross section
 Provider, expert
 Commissioner enabled - Sharing of clinical work
 Provider need guided by communication, LA, L and D
 Engaging with GP's

Added value
 Big meeting – annually



have a purpose

local and wider inclusiveness
 Task and finish
 Groups – consultations
 Themes and generic

Local network of support services
 Sharing knowledge and practice
 Forming networks, and opening pathways
 Local and national politics and potential to challenging
 Commissioning
 Access to funding for initiatives
 Collaboration with others

Issues that people with Id have mental health as well a physical health

Resources (sharing what other resources are out there for health carers)
 Sharing ideas / Resources
 Personal experiences

Anything else you want to say about local meetings?

How would local groups be maintained?
 Website presence for local groups?
 Hosted by HEEKSS?

Having a theme – people being asked about it
Making meetings accessible to everyone (re YouTube) not just those attending in person.
Accessibility made in local meetings (i.e. K and S and S).
Balance though – people need to be there to make it successful.

Good notice for quarterly meetings – planned a year ahead
Accessible for public transport as not everyone drives
Good biscuits

It's easier to get there
Bringing differences to meetings.
Making sure it is wider than LD community – letting other professionals/support networks know e.g. police, housing, parents/carers, charities, advocacy etc.

Patient experience
There aren't enough people with a LD here!

Multi-agency – need to share good practice going on outside NHS as well. Public Health England agenda.

Empowerment, education, information for parents/carers others.
GP education for others
Stop the battling and bring people together

How do they work?
Not a meeting for meeting sake
Conference calls – initial meet ups and then using technology/webinars
Need to be cost conscious
Information sharing

Keeping safe – space to discuss issues that affect people in their lived – involving people
Sharing resources

Skyping in
Priority / wish list
Shaping practice
Quorum – vs – membership – vs – all
Accessibility

Timings and when it happens Social care
Rotating days of meeting to capture as many attendees as possible What is local? – defining geographical banners Method of communicating meetings Interactive elements to meeting Inclusive of service users, carers
No – it would be nice to go to one

Champions – A champion is someone who is passionate about something and will speak up.

Is it a good idea to have champions?

Yes	No	Don't know
1		
1		

4/4		
1		
1		
1		
1		
8		

What things need a champion for people with learning disabilities?
Baseline assessments for people with Downs Syndrome – publicise the need.
Champion for healthcare education in LD – campaigning for improved training in LD for GPs, nurses etc.
Champion for transition – supporting paediatricians, GPs etc.
For continuing healthcare/people with pmlD/people from ethnic minorities.
Importance of identifying champions within the community.
PBS – someone involved in giving direct support.
Accessing health screening including GPs and liaison nurses across board AHC (with CYP as well?)
Multi professionals user by experience/carers etc.
Employment facilitation for pmlD
Criminal justice system – CPs, police, probation service, housing
End of life care – hospice – joining together services/ speech/OT, nursing
Well-being – health lifestyles, diet, exercise.
CYP –working with schools etc to promote good health
Gives person a boost
Enables everyone to be a leader
For service users without confidence – a voice
For any of people with a learning disability needs eg. Nutrition, exercise, health and well -being, employment, budgeting, other health conditions e.g. epilepsy, diabetes, social and relationship awareness, Downs Syndrome.
Communication – people’s views – service users views
Link between people with ld and services/supporters
Employment and education
Access to health services
Meaningfully capture what people’s concerns are – forum/meetings/questionnaires
Arrange local events/share information about local information
Sharing good stories
Charity events/fundraising/with prizes
Tell people’s stories
Linking with other champions – health etc.

Primary care/secondary care
Transitions vital
Mental capacity
Families/carers
We need to take the C of P to people with Id; meetings need to be evenings, weekends etc.
Whatever interested in – work, health , eyesight
All key stages of people’s lives: education, transition, family
Needs to be led by people with learning disabilities – what do they want a champion for?
Champions to help navigate the system – DST, capacity assessment etc.
Where to send referrals (make it easier for people using the service)
Champion in uni sector for education
Champions could be joint working roles
STOMP
Health/social care
PBS
Navigate through the silos to bring people together
Develop local networking
sexuality
Careers/jobs
Education in general
Be in touch with current projects etc and communicate
Cancer Screening – health – how do we make it important to pwld? – how to enable them to get this – access it
Accessible forms/information
Capacity – informing GPs how to speed up the process. Working in multi-teams
Pwld – telling us about their health experience
Making residential services ‘person centred’
Changing culture of organisations/staff – staying up late.
Looking at discrimination
Community engagement – social care support
Commissioning of services – 1:1 support / training/ supervision
Safeguarding
Family – the importance of family, relationships etc. friends

Friendship group
Again – what does exist? – palliative care – link KSS / dementia / behaviour /AHC/ pharmacy – STOMP / GP-LD Across CCG / Workforce and career / expert by experience
Spokesperson on specific areas - passion and credibility – (lobbyist)
Support for champion essential and clarity for the role
Growing (in) expertise
Local networking and resource
Dental, restrictive practice, human rights, self-advocacy, transport, employment – accessing life-long learning, education, sex and relationships, healthcare, end of life, PBS, care planning and case planning forums, benefits
Recruit a service user expert in their local group – bottom up, not a top down approach
Mental health. People don't think someone with a Id can also have mental health problems together. They treat one but don't link them.

Anything else you want to say about champions?
We are interested in local meetings
Would champions help with signposting to resources/people/services for their particular speciality? Including training etc. Local knowledge
Need to know more what they would be doing and who the audience is Good idea Would need support
They are important Continuity of champions if someone leaves/moves Care role
They need support to carry on in the role – mentor, debrief
Mindful people giving time – carers expenses
People recognise importance of the role to allow people the time to do the role and give them additional support to achieve it.
Logistics, setting up meeting
Changing the culture – NHS doing more with less resources. Use DAO as an example – workers are often ex-users.
Hep-C champions, run groups etc. NHS doesn't have this.
“a champion” or “champions” – different role – we could all be champions “Champions” – expected to know everything.
To be the person to ensure certain aspects of LD are communicated.
Good idea
Passionate people about the topic
JD – how are they supported, role description, Ed. – how, time and permission
Develop an app – web and accessibility Training ie. Media training Representation on e.g. STP workstreams, CCC's, AHC Local/national/international Funding and sustainability
Champions are good because they can speak up for other people on

issues that others think are important. They get the opinions of other people and get to know what other people are thinking.

Finding individuals with keen interests – various specialist fields
Recognises each person's prejudices and biases
This could be about self-awareness of the champions
Attended a course on unconscious bias – accept differences and promotion diversity
How do we go about developing the champions?
Comm/people skills. The ability to enable people to own strategies rather than be told.
How do we find out what skills people have?
Networking, areas of interest
Skills audit
Use of internet?
Twitter, Facebook, blog – for sharing
Making sure people (nurses, professionals) share the information with service providers e.g. referring people to specific websites etc.
A willingness to have a difficult conversation between different professional services
Two way comms/sharing information/practice – local meetings?
How do we fully engage people with Id in championing/technology
Educating people to use media forms – what is available?

Do you want to be a champion or do you know someone who would be a good champion?

Names
<p>Milly Foster (recommended by colleagues at Avalon) Degree in health and nutrition Milly.foster_avalon@yahoo.com - South East Kent, Cant/Ash/Rams Natasha? – sorry no info</p>
<p>Sam McKinven sam.mckinven_avalon@yahoo.com</p>
<p>Would like to know more before committing – but in theory yes Mark Plowman – m.plowman@southdownhousing.org tel 01273 405822 Philippa Harris – philippaharris@nhs.net Lisa Harnington) pene.stevens@nhs.net Sarah Walker) – accessing health screening - pene.stevens@nhs.net Marion Jennings (for interest) jenningsm@isbu.ac.uk Penny Clark – EOHE ?? – sorry no info</p>
<p>Vanda Duarte – Surrey and Borders – vanda.duarte@sabp.nhs.uk Sarah Haslam – Dartford and Graves London – s.haslam@nhs.net Rebecca Tucker – L’Arche – rebecca.tucker@larche.org.uk</p>
<p>Paddy Behan – PBS - pbehan@pbsuk.org</p>
<p>Possibly if topic relevant – Michael Hobb c/o Daisy Anne Hack – daisyanne.hack@nhs.net</p>
<p>Grace-Eyre Foundation (sharing experiences) i.e friendships, travel buddy scheme, ambassador group Contact – James Rich – jrich@grace-eyre.org</p>
<p>Nicky Wells, 78 The Limes, Kings North, Ashford, Kent TN23 3NY 7855 99 – no email</p>

Using the internet – we have a blog – this is something we put on the internet for other people to read.

What else would be useful to have on the internet?
Database of all members of CoP Local group contacts List of experts List of champions
Forum – for specific subjects/discussion groups Podcasts – could these be useful for ie difficult behaviour hints and tips. Different topics Central resource – everyone puts in practical tools. Knowledge hub.
Signposted links to resources e.g. papers, peers and experts
Real stories about people Research tools – books and articles Local meeting information Contact numbers/services/partnership boards Calendar of activities –update regularly Providers first would help people with health/access Easy read – share information How to use internet safely
Could we have a session in people’s day services – CofP session? Sent information to day services etc and get them to facilitate so people can all share their experiences and feedback etc
How the blog gets out is important – some people don’t want to go to the website Access to Facebook and Twitter. Others don’t use FB or Twitter Emailed newsletters – what’s going on – links to blogs, info etc. Blogging podcasts (audio) with link CoP website with email update monthly ‘tasks’
Never heard of it? How do we know what it is about? Too many sites signed up e.g. Care England VODG etc. And information too much Could paradigm or BILD be the main link.

Hubs to discuss key topic (Smart website) Quality vs quantity
Colour changes To many menus Video diaries? Champions blog
Facebook group Good indexes Centralising resources APP developed to provide information
Calendar of event – Region Signpost – what is LD? Champion – contact details Contact – H & C across providers
Database – paid person
?Facebook YouTube video Instagram Visual tours – for LD users Internet dating Sharing information Training and skills webinars
Don't know

What else would be useful on the internet? Or on social media – this is things like Facebook or Twitter
Twitter chats Facebook live Calendar invites to members/chats Other options? For people not on social media
Tend to use as an information source Need to keep a clear boundary between professional and personal
Letting people know about the CoP on Facebook and Twitter Need to do this safely
Facebook group
Closed group e.g. Yammer
?not utilized fully but an option skimming headlines Local MP's
Twitter quite complex. May be tricky Instagram
Way of searching for available information Having blogs on health, relationships, travel
Linked in Skills for care/health Pinterest PH - Twitter
Twitter chat Accessibility What's app group
Linked in Pinterest
Don't know

Webinars – these are meetings over the internet – You can listen to people talk on the internet about care and support. You can ask them questions.

Are you interested in doing this?

Yes	no
1	1
4/4	
1	
1	
8	

What things do you want to listen about on the internet?
Anything that helps to support aims of CoP
Workshop presentations experienced today Other people's experience of different systems
Opportunity to find out about the meetings Topic specific – action/voting – when things are happening e.g. services changing/moving benefits changing/new things
May be a webcast of a meeting? Webinars of meeting Live cast Example 1-2 minute webinars e.g. Mental Health Foundation example some not sure want to take part on a webcast/webinars
Key topics to discuss certain topics
Webinars could be a safe place for pwld to discuss ideas/issues etc.
Just use – pre-employment training / short sharp
Web designer Paid and resourced Accessibility – all key and crucial
Local government policies, and implications for people with ld Research New projects and initiatives
Don't know

Anything else you want to say about webinars?
Consider people's ability/capacity to access them
Like follow though it enables as can track back County information Potential for involvement in research
Access to computer/training
We all need IT training!! IT needs to be good enough Need space to listen to the webinars etc in your workplace
Difficult to participate
Quality of technology and accessibility may be an issue Text can be an issue
Time at day/week advertising
Support with technology for those new to technology and webinars As it is it may be too complicated for some service users Expense of pre-referred technology
I don't feel confident about using computers

General discussion

Meeting – what sort of meeting? (Carl)
I'm involved in transforming care partnership from North of England (Carl)
DM Facilitator
TCP – is aimed at discharging people who have lived in long term hospitals and also about stopping people from being put in there. (Carl)
Ensuring that one is not locked in one service but a combination of service provisions – health, forensic, GPs, and social care – all working together (Nash)
Dynamic register? Responding to crisis situations in the community
Sharing a learning or partnerships (Nash)
Challenge – collective risk taking between different organisations or even different professionals
Care and treatment reviews need to happen/start from prisons (for pwld) – (Carl)
Linking local initiatives with national (DM)

Appendix 2: The KSS Tree Evaluation

- Empowerment for person centred practice/care
- Very informative. Great to hear about other services and ideas. Thank you
- Talk about it!
- Excellent opportunity for networking
- Thank you for a wonderful day, it's been very useful and interesting
- Positive, engagement, sharing, STOMP, and educational
- Support from family. Overminds, let them have control over their lives, freedom life throughout, support the people
- Great networking opportunity
- Networking sharing knowledge and ideas
- STOMP, positive behaviour support, mood cards, great sharing info
- Fun!
- Motivated
- Challenge and support
- Professional network reflection
- Cuts
- STOMP, mood cards, positive, good interaction, educational
- The lunch was brilliant!!
- Welcoming and stimulating
- Involvement
- Networking and not so new
- Good well organised day. Great examples used 'real life'
- Great, inspiring and interesting
- Nice opportunity to most people working in different areas
- Warm, inclusive, informative, great networking, inspiring. Well done
- Lovely to renew relationships
- Shared learning
- Reminded how privileged I am to work in the field!
- A professional nature and engaging event
- New idea generator!
- Great opportunity to share good practice
- Great to catch up with past colleagues
- Culture
- Learnt lots about job carving. Really positive work!
- Job carving. Creating roles for people with LD
- 3rd workshop remarkable

- Ideas, improved, practice, person centred, inspire, together is better!
- Sharing knowledge and ideas very useful
- Inspired
- Mindfulness for the staff and service users – I love this idea
- A perfectly formed conference...personal and diverse!
- Enjoyed talking about case studies!
- Networking, enjoyed workshops, increasing knowledge, support, information sharing
- Enjoyed meeting 'old' friends and new people
- Mood cards, planning for when you die was very good!!
- Food for thought
- Everyone was friendly, Mi gusta a to do
- Great to meet new people with shared passion
- Positive and engaging
- Mindfulness for staff teams
- I enjoyed the workshop, STOMP and lunch
- Very enjoyable
- Sharing ideas to create a positive future
- Action planning?
- Exciting, inspiring, fun, informative, promising
- Fantastic lunch!
- Good networking, variety of information and great lunch!
- Sharing knowledge
- I enjoyed the STOMP session and being able to share ideas with other teams
- Mutual respect and understanding
- Interesting and enjoyable
- Co leading was a good way to run the workshop
- Thought provoking and problem sharing
- Information, meeting people, learning new things, and good resources
- Being around positive people
- Informative
- Friendly, enjoyable, learnt, great
- Challenge, good lunch, joy, collaboration, ideas
- Reflective learning
- Motivated and inspired to be a stronger advocate and supporter of everyone with learning disabilities
- Joined up working, hope for the future
- Good networking opportunity
- Powerful
- New opportunities, new information, and good experiences

- Informative, new opportunities, and inspiring
- Interesting and informative
- Meaningful engagement
- Good variety of talks!! Something for everyone
- Workshops, networking, STOMP, well organised, and collaboration
- Mood cards are brilliant
- Really enjoyed meeting old and new friends, all of the workshops, lunch, cop discussion, better: signs to talking space
- Gemma loved it too
- Loved it, amazing, awesome, brilliant, exciting, and inclusive
- Roots are needed
- Better understanding

Appendix 3: Delegate Evaluation and Feedback

Tell us what you thought about the day

What did you like about today?

- Offering of different workshops throughout the day
- It involved different services and service users
- Andrew's story
- Sharing ideas and experiences
- The learning job work
- Networking
- Seeing old colleagues/friends
- Hearing about stomp and mindfulness for staff teams
- The opportunity to network with
- Friendly
- Welcoming
- Learning
- Mind blowing
- Energy
- Meeting stakeholders
- Sharing knowledge
- The cross section of attendees and speakers
- All sessions attended
- Get some ideas to take away
- Warm, friendly, informative, inclusive
- Great networking
- Inspiring
- Lunch
- The way networking and sharing experiences was encouraged both in and outside of workshops
- Friendly
- Informative
- Good group sessions
- Sharing of information
- Good mix of people/professionals/books/Quals

- Co-chairing by Andrew, and a high level of engagement by the people with LDs present. Quality of workshops – especially they are about Cedar House's recovery college (something didn't have more time), which was so inspiring. Networking opportunities.
- Hearing about new projects
- Talking with new people
- Meeting different people
- Interesting presentations
- Discussions with the various others and the relaxed programme
- Variety of subjects and attendees
- Today has been great. Very interesting. Well organised. Very informative
- Coproduction
- Inspired/interesting groups/workshops
- Meeting people, connecting people
- Networking opportunities
- Sharing ideas
- Networking opportunities
- Discussing creative ways of working and learning in the future
- Variety of shared good practice
- Networking opportunity
- Focused work groups
- Seeing colleagues
- The workshops
- Group exercises
- Co-chairing
- Passionate people
- Meeting old friends and new ones
- Good range of workshops
- Food
- Parking
- Informal but purposeful
- Networking
- Workshops
- Well organised
- Meeting new people and learning new things. Good food
- Networking
- Refreshing skills
- The workshops and there diversity
- Learning about different experiences.
- Meeting different professionals

- The opportunity to meet other professionals and to share the desensitisation project
- Small group, Sally ensured we imagined and shared ideas was very positive
- Meeting different professionals
- STOMP – very interesting work
- Networking and information sharing
- Informative, brought me back in thinking about practice.
- Networking and gaining new ideas
- Informative
- Meeting people/networking
- Learning new things
- Good resources/tools
- So many people from different areas – i.e. private charities/acute trusts and community
- Group discussions and experience
- The opportunity to network with a range of professionals from other areas
- Great networking opportunity, very informative and liked the stands
- Really enjoyed it, shared learning and professional networking
- Representation from multiple agencies; info presented in a clear and concise way; fluent talks by people from L.D. community
- Meeting other people from the LD community
- Positive approach to changing the lives of people with a LD
- Meeting people from different organisations and disabilities
- Workshops useful and liked choosing which to attend, and meeting other professionals and sharing knowledge
- Meeting colleagues from autistic of learning difficulties, reflecting of their ideas and “stealing” them
- Excellent
- The opportunity in meeting lots of different professionals that could share and think about new networks
- Having the opportunity to meet and have discussions with other professionals and people with different backgrounds – sharing ideas on improving community practice
- Interesting topics and diverse options for group sessions/workshops
- Planning for the future of the cop – how do we make it work and have a sustainability of its aim

What didn't you like about today?

- The weak coffee!

- Nothing
- Very weak coffee
- Coffee too weak
- Nothing
- Nothing
- Poor positioning of posters
- M20
- Was a bit cold!
- Rooms too cold!
- Quality of refreshments and lunch very poor. Air-con was rather enthusiastic!
Lack of information about where to find the car park
- Queues for lunch and room temperatures, superficial in content of the day!
- Food and drink arrangements
- Not enough time to discuss good/success stories
- Being indoors on a sunny day!
- Enjoyed the whole day
- Coffee!
- All fine
- Rooms were cold (esp green room)
- No social care represented
- No primary care
- Would like details of participation list to include job titles so know whose who
- Time constraints
- Recovery college
- Shared take had longer or, most stage forum
- Nothing
- More involvement for service users, people with learning disabilities
- We are still preaching to the converted. We all know about good practice. We need to get the message spread wider to people who don't necessarily know
- Very cold
- It was very cold
- Nothing
- Too cold!
- Too cold
- The distance to travel more involvement/attendance of people with learning disabilities as delegates
- Slight disorganisation this year
- Nothing
- Temperature of the room
- All ok

- How cold the room was
- Nothing
- STOMP
- Epilepsy training
- The rooms were quite cold
- It was very cold in the break out rooms

Were you happy with the organisation of today's event?

There was 45 people that were happy with the organisation of today's event (replied YES)

- It felt it was well organised
- Yes, ran smoothly, interesting and interactive
- Yes – was very well organised – lunch was great too!
- Yes, well done all!
- Yes, though time management could have been better
- Yes, clearly understood and communicated
- Well organised
- Yes very happy, thank you to everyone that has organised it
- Yes, very well organised
- Excellent
- Yes the majority perhaps could have been useful to have it over 2 days
- Well
- Well organised
- Very happy
- Very organised and structured and lots of different events
- Yes, very organised and good communication and made by the event coordinator
- I thought it was very well organised
- Food was lovely
- Availability of hot food
- Yes, very happy
- Yes, organised well and grateful to catch up lost time. Lunch was great option for vegetarians and healthy option

What did you find the most helpful for you?

- Planning for when people die

- Talking to the SeeAbility team
- The 3rd workshop
- See under likes
- The workshops
- It was very helpful and I can take this away
- Colour codes on workshops!
- The time table
- Networking
- Networking
- Hearing people's stories where practice has been successful, sharing ideas and getting information that helps you challenge your own practice. STOMP resources will be particularly useful
- Networking opportunities, workshops and discussion of future directing for cop
- Thinking about how to move forward with the community of practice
- Meeting service users and other health care professionals
- Finding out about projects and more going on in the field
- The workshops were more helpful to me
- Group discussion
- Networking
- Workshops for sharing ideas
- Meeting key people and information sharing
- Contribution to others programmes
- Service user insight
- Workforce/employment workshop
- Exhibit @ KCC
- Stomp work
- Networking
- Workshop handouts
- The workshops STOMP especially
- Learning about different points of view and having a better understanding about how people work and the different services out there
- Sharing experiences and professional discussion/problem sharing
- It was all generally excellent
- Being able to choose workshops
- Recovery college session
- Small workshops which enabled discussion and debate
- STOMP, the discussion of how to move forwards with the COP
- Statistics
- Being given slides of power point presentations
- All of the workshops

- Learning – others feeling what they are doing and where and organising
- Seeing what is going on and what is happening in Kent
- The workshops very useful
- As the above
- Epilepsy workshop
- The network presentation
- I quite enjoyed the workshops especially 'planning for when you die'. I also find it useful to get the views and involvement of people with a learning disability
- Really enjoyed discussion and STOMP and palliative care
- Networking. STOMP was great too

Were the speakers easy to understand?

There was 46 people who thought the speakers was easy to understand (replied YES)

- Yes – no problems
- Yes, I found all of the speakers easy to understand
- Yes very comprehensive
- Very
- Yes, great to see user lead pages of the conference
- Yes very clear
- Very
- Yes – bit quite in one room
- Yes – very
- Very well

Is there anything else you would like to say?

- Keep us working together and learning more. Thank you and well done
- Hope we can harness the energy today to help keep the cop sustainability
- Thank you for organising a good day
- Thank you and happy to be GP champion
- Wonderfully informal and lots of useful information
- Fantastic
- I would like to expand specific topics and have wider discussions about them. Too many subjects with insufficient time to discuss and learn
- Thank you
- Thank you

- Could there be 'themed' events e.g. PLD and prison/SEN Schools/annual health checks. Thanks
- Important to have clear priorities and direction to sustain cop
- Thank you
- Great lunch, great venue
- Positive event, good experiences shared.
- The right way forward!!
- Really enjoyed this, thanks!
- Would love to deliver a workshop next year
- Not sure what is going on in West Sussex community of practice where I've worked for them for 17 years
- Very well organised
- Very good! Hope to come back next year