

Kent, Surrey & Sussex
Learning Disability
Community of Practice

Kent, Surrey and Sussex Learning Disability Community of Practice

Conference Evaluation 2016



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

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This evaluation was produced on behalf of its members as record and summary of themes and discussions that occurred through the launch event. We hope it will also be of interest to individuals who have a learning disability, their families, friends and any other groups that may provide or offer education and/ or support in the area of learning disabilities.

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Easy read summary



On 15th June 2016 the Kent, Surrey and Sussex Learning Disability Community of Practice held an event in Crawley.



The purpose of the Community is to support carers, care workers and professionals to:-

1. be person centred
2. provide the best quality care and support
3. improve equality and access



This Community cherishes the experiences of experts like people with learning disabilities and family carers.



The Community used the new website www.ldcop.org, social media and telephone conferencing to organise the event.



Participants at the event told us what they thought of it in three ways:-

- Twitter
- One word evaluation on cut out hands
- Post event survey



Through reviewing this feedback we found participants liked:-

- Being touched and inspired
- Hearing from experts and using social media
- Asking questions and getting support
- Having a safe and fun place to learn



In the next year this Community wants to :-

1. Develop a three year work plan
2. Use the website to share inspirational stories
3. Develop research and leadership



This Community will continue to cherish experts by experience in all its activities.

Background - Précis of first three years of the Community of Practice.

In 2012/13 staff from East Kent Hospitals and Canterbury Christchurch University worked with local people across the county to form the Kent and Medway Learning Disability Community of Practice. 60 people attended a facilitated event to establish a shared purpose for this Community, that of the eradication of health inequalities for people with learning disabilities by supporting carers, care workers and professionals to be: -

1. Person centred
2. Provide the best quality care and support
3. Improve equality and access

Communities of Practice

Wegner-Trayner (University of Brighton, 2013) identifies that networks and communities of practice (from here on referred to as Community or communities) are social structures where learning takes place. Networks are often a set of relationships based on individual and personal rationale to connect. These tend to be individualised and maintained through information sharing, knowledge creation and problem solving. A Community draws r individuals together, developing a shared identity, and represents a collective intention to steward or curate a shared purpose, and sustain learning about it.

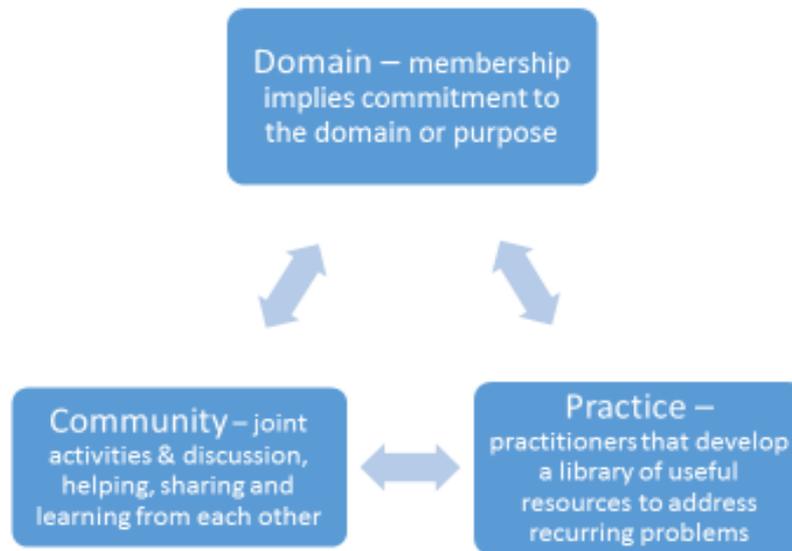
In Kent and Medway it was acknowledged there were many networks of people who had a stake in supporting people with learning disabilities. What appeared to be absent was a Community that would draw these networks together, harnessing these passions and motivations whilst enabling all involved to improve their work through this regular interaction.

A community of this kind can be considered to be a social learning system, one based on the social theory and anthropology (Giddens, 1984; Foucault, 1980) along with Forder's (1976) conception of systems theory – philosophical, raising awareness / education and learning, practice appraisal and intervention, contribution to understanding of processes involved.

Wenger-Trayner (2015) outline three main concerns of Communities that are integral to the community's development.

Three concerns of Communities of Practice

(Wenger-Trayner, 2015)



According to Wenger-Trayner (2015) these concerns- and in particular the Domain- make the Community distinct from a network. The shared identity that is created enables a more reflexive and flexible membership and leadership, not relying on individuals, resources or contracts to have activity occur.

The distinction that this Community poses to this model is on the area of practice. From the outset in 2013, the Community was founded on values of inclusion and accessibility throughout all its activities. Each annual conference has encouraged accessibility, engaging people with learning disabilities to present either on their own or in collaboration, and in the East Kent Hospitals University NHS Foundation Trust (EKHUFT) Clinical Education Learning Disability Workshops (K&MLDCOP, 2015) which were co-facilitated with experts by experience who have been employed as freelance consultants.

Along with people with learning disabilities the Community have actively sought local partners to engage with the shared purpose, along with EKHUFT, Canterbury Christchurch University, and Kent Community Healthcare Foundation Trust, the community has been eager to engage all individuals and organisations to support this social learning system, and progress the activities of the Community. This has also included academics and speakers from outside the region, to support local events and projects. One such example of this has been a 'Lifestory' project supported by Professor Jan Walmsley, which East Kent Mencap are currently developing. More recently this has resulted in an organisational Fellowship with the England Centre for Practice Development and support from the Kent, Surrey and Sussex local office of Health Education England.

Wenger-Trayner's (2015) model of Community is underpinned by a value of mutuality, which has little in the way of hierarchy and lends itself to the new forms of organisational systems such as holacracy (Robertson, 2015). These systems are symbiotically linked with society's understanding and engagement in possibilities of the internet and social media. To this end our Community has actively engaged in online activity and social media to allow a continued online presence and to ensure regular email updates reflect the purpose and geography of the community.

Conference Planning

Along with establishing a social media and webspace presence, those involved in developing the Community have used a variety of communication methods to ensure activities and tasks are shared and achieved. Initial face to face

meetings employed a mixture of practice development facilitative activities and traditional business meeting discussions, and established 12 month plans to organise the team to arrange the annual conference usually taking place during or before Learning Disability Week in June. Following this, use of email, social media, and of significant value, short weekly telephone conferences enabled regular Plan, Do, Study, Act cycles to ensure the various conference arranging activities were handled. These included: -

- Inviting Keynotes
- Organising event logistics software
- Publishing invites & Call for Abstracts, Partner invites
- Venue liaison
- Participant hospitality and equality of access
- Abstract reviewing & feedback
- Event scheduling & role negotiation

The 2016 Community Conference provided three data sources that enabled the organising team to review progress, these were the number of:-

- Participants registered
- Abstracts received / Workshop presenters
- Marketplace stalls volunteers

This data was accessible to all the conference organisers via the online systems employed and provided a basis for further qualitative conversations speculating and interpreting, and planning actions to make further improvements prior to the next call.

Event Evaluation Data Sources

Three sources of data were employed for evaluation of the event itself: -

- a. Social media transcript from the day of the event using #ldcop16 (KSSLDCOP, 2016)
- b. One-word evaluation on paper cut out hands (KSSLDCOP, 2016)
- c. A post event online evaluation form

A thematic analysis (Paterson et al, 2001) of the social media transcript was undertaken to offer an indication as to participants' thoughts, feelings and experiences during the event. This themed data can be found in appendix 1.

The one word evaluations which can be found in figure 2 also provide some immediate indication of participants' experience of the whole event, and while reductive, demands the individual to be creative. The words written by participants can be found in appendix 2.

The online evaluation had been incentivised through the use of a prize, the final response rate for this was 16%, however of these most wished to be actively involved in the on-going development of the Community of Practice. Interestingly those that responded to the online evaluation identified that they found out about the conference via a direct invite, with only one respondent identifying they booked following seeing the flyer on social media. Perhaps unsurprisingly the keynote speakers were rated most highly.

Two free text boxes allowed respondents to make comments about their reasons for attending and the most beneficial aspects of the conference. These responses have been themed and can be found in appendix 3.

A secondary analysis, which can be found in appendix 4, identified four main themes for consideration:-

- Participants' Inspirations, emotions, humanity and learning
- Inclusive innovative learning involving experts by experience and information technology
- Whole system workforce network questions
- Fun and safe environment for learning

These methods and results were then shared and consulted on at a meeting of those that expressed interest in leading the Community in the future. This cohort was made up of staff from higher education, healthcare professionals and independent consultants.

Results

Participants' inspirations, emotions, humanity and learning

The overwhelming impression that emerges from participants' feedback across the data sources is inspiration. The keynote speakers were the key to this providing personal and professional testimony, emoting and invoking that emotion throughout the participants. Dewar (2009) bases her framework for evaluation on the power of memory associated with emotion. In this context the participants' feedback indicating that speakers had been powerful, motivating and above all emotive and emotional, will ensure that the learning will live long in their memories.

Comments such as "teaching us and making us laugh in equal measure" and "Stand up change hearts and minds and raise awareness" from the social media transcripts offer some indication as to the experiences of the participants in the moment.

While the post conference evaluation had a 16% return rate – somewhat lower than expected based on the incentivising of its completion- those that did respond observe the 'powerful speakers' and indicate a longer term rejuvenation, identifying the event as 'energising' and 'refreshing'.

Inclusive, innovative learning involving experts by experience and information technology.

Participants identified that the power of the event had been in the inclusive element. Feedback indicated two distinct elements to this inclusivity, firstly the leadership and involvement of people with learning disabilities and family carers throughout the programme. Respondents identified that all three keynote speakers were experts by experience either having a learning disability or having a child with learning disabilities, identifying they were 'passionate and funny advocates'. This leadership of the event provided a framework for the professionals' concurrent sessions, and touched, moved and inspired the participants.

The second form of inclusivity related to participants' ability to contribute using social media. Along with adding references, comments and queries, participants were able to engage people and account outside of the event in conversation drawing more people into the conversation and community. The conference had 88 different Twitter accounts contribute to the transcript (KSSLDCOP, 2016). Respondents acknowledged the richness of this feedback saying 'Participants add external evidence', 'Engaging participants both inside and outside of the room #inclusive' along with 'gaining understanding', 'regional and strategic perspectives' and were able to 'share new ideas and innovations'.

Whole system workforce network questions

This theme draws together the comments, queries and questions that participants began to inquire into and explore as a response to being at the event, and the methods that individuals used to consider these issues. Many of these related to workforce training and education issues, a good example of this was 'we should get service users more involved in planning courses at ****' and 'How can we best prepare healthcare staff to make best interest decisions appropriately?'.

The methods that individuals used to explore these issues included the use of social media, which had the impact of drawing others into the conversation, while others reflected that they valued the power seen 'friends... connections and contacts...(for) networking'.

Fun and safe environment for learning

The content of the event ranged dramatically from personal experiences to professional programmes of care, to education and training, and reports of reviews of standards of care and support. Speakers used a variety of different methods to explore their chosen subjects to make them engaging.

Participants and respondents appeared to enjoy this mix of approaches to entering into the inquiry and exploration of contentious issues - 'Safe environment to share complex and challenging information – mortality, sepsis' and 'Language risk, suboptimal outcomes'. Other presenters facilitated and enabled the participants to take part in their session, identifying ways that they had found useful in engaging people with learning disabilities in public health messages '...masterclass in engaging an audience!'.

Discussion and Recommendations for the Future

Applying feedback from the Evaluation meeting on 19th October (see appendix 5), several areas for development were identified:-

Audience and participants

It was acknowledged that the Community of Practice would likely continue to attract people whose core activity is the support and care of people with learning disabilities. However continued targeted engagement projects would be necessary to involve advocates and activists that have experience of people with learning disabilities. This group is often made up of those that have had recent experience of investigation or complaint, have family members who have learning disabilities or who have worked in learning disability services and have moved away from that arena. While the latter two groups tend to remain latent supporters, the former groups are usually transient requiring support and guidance to influence systems and processes to make adjustments.

Activities to engage these cohorts, and therefore extend the reach of the aims and objectives of the community, will support the development of 'insider' professions. Two such professional groups were identified as 'Insiders' - those of Learning Disability Nurses working within mainstream organisations such as Acute Hospitals, or with GP surgeries, and Safeguarding Practitioners.

Capturing inspirations and wow moments

Acknowledgement of the foundations that the community has developed, both in people, and systems. is a substantial basis for further developments to share and engage others. Two such examples that were explored were through short vignette films identifying 'wow' moments which could include outcomes for people with learning disabilities or those that identify the assumptions that underpin the inequities on our health and social care systems.

Within It was acknowledged that through the Community event new creative film makers had joined the community. It was also identified that as so many people now carry smart phones the possibilities for capturing these moments was primarily based on the individual's willingness to do so.

The Community website was seen as a vital hub for activity, and in particular the Guest Reflective Additional Blog (GRAB). Building on the idea of the importance of collaborative whole system working to ensure person centred care and support, participants recommended a multi-perspective blog, where opinions and observations on an experience could be gathered from several individuals involved to elicit successes and challenges inherent in the system.

Along with these larger projects, some attendees created haiku poems from the one word evaluations, and recommended a secondary analysis of the twitter transcript to elicit the uniqueness of this Community and creation of word clouds and strap lines.

Leadership development and education

The IDHEKSS report (2016) outlines the local individuals and organisations that have successfully attained support to develop their services to people with learning disabilities and share their findings. While these outcomes will provide rich evidence for sharing at the annual Community event, it was acknowledged that the Community would also benefit from developing leadership opportunities. A Community led aspiring/ leadership course would allow participants to further practice inquiries aligned to the Community shared purpose, and could also harness Higher Education Institutions' (HEI) support with robust research, development and evaluation techniques. Based on the learning disability workforce being widely spread across the whole system, a course such as this would bring benefits for participants and for stakeholders, and would also offer valuable insights into integrated care as the Sustainability and Transformational Plans are realised through the Vanguard sites and Integrated Care Organisations.

As a result of the 2015 budgetary spending review, changes in funding for healthcare education places HEI's in a prime position to work both collaboratively and innovatively to ensure the next cohorts of health professionals have sufficient knowledge and experience for their area practice, be that specialist learning disability professionals, or more mainstream professional courses. This Community believes this partnership with HEIs and academics is integral to its shared purpose and as such would wish to support activities in this regard.

In this context, this may involve opportunities for collaborative, transformational, innovative research and development to support local leadership, enabling person centred practice and eradicating health inequalities, and include new educational course designs, such as Massive Open Online Courses (MOOC).

Recommendations

1. This Community will establish a three year plan for supporting and engaging learning disability specialists and mainstream health professionals in its shared purpose.
2. This Community will develop its web based presence to share inspirational moments in a variety of media.
3. This Community will work with HEIs, local people and services to use transformational methodologies to develop leadership aligned to the Community's shared purpose in KSS area.
4. This Community will consider how cherishing its non-practitioner stakeholders and their views will further improve the value of its activities.

References

Dewar, B., Mackay, R., Smith, S., Pullin, S. and Tocher, R. (2009) Use of emotional touchpoints as a method of tapping into the experience of receiving compassionate care in a hospital setting. *Journal of Research in Nursing*. Vol. 15. No. 1. pp 29-41.

Forder, A (1976) Social Work and System Theory. *British Journal of Social Work*. 6 (1) 23-42.

Foucault, Michel (1980) *Power/Knowledge: selected interviews and writings*. Edited by Colin Gordon. New York: Pantheon.

Giddens, Anthony (1984) *The constitution of society: outline of the theory of structuration*. University of California Press.

K&MLDCOP (2015) Learning Disability Workshops. Available online at <https://kentlivewell.wordpress.com/learning-disability-workshops/> last accessed 18/10/16

KSSLDCOP (2016) 2016 KSSLDCoP Evaluation. Available online at <https://storify.com/KSSLDCoP/ldcop16-in-tweets> last accessed 10/12/16

IDHEKSS (2016) Workforce development for people with intellectual disabilities: One year on. Available online at <https://idhekss.files.wordpress.com/2016/04/idhekss-one-year-on-report-ver3-6-online.pdf> last accessed 18/10/16

Paterson, B Thorne, S, Canam, C, Jullings, C, (2001) *Meta-study of Qualitative Health Research : A Practical Guide to meta-analysis and meta-synthesis*. London : Sage.

University of Brighton (2013) Learning in landscapes of practice. [Video file] Retrieved from <https://www.youtube.com/watch?v=qn3joQSQm4o>

Robertson, B (2015) *Holacracy: The New Management System for a Rapidly Changing World*. Henry Holt and Co : New York.

Wegner-Trayner, B & Wegner-Trayner, E (2015) Communities of practice a brief introduction. Available online at <http://wenger-trayner.com/introduction-to-communities-of-practice/> last accessed 26-9-16

Appendix 1 Social Media Transcript Thematic Analysis

Social Media Transcript Thematic Analysis		
<p>Participants Inspirations, emotions, humanity and learning</p> <p>Humbled, inspiration. Learnt lots, a lot to think about, time to reflect #strive proactive conversations for proactive care Better flow of information increases reasonable adjustments laughing and crying teaching us and making us laugh in equal measure Crucial networks Suggestions for using our shared wealth present engagingly –simple messages, videos, role play, fun. Stand up change hearts and minds and raise awareness (inspiration) Mindfulness Theme – humanity not reductive Overcoming barriers, promoting educations, sharing information, and beating boundaries – how we learning is important in overcoming barriers Making changes and rocking boats’, ‘tears shed, gauntlets thrown, plans refreshed’</p>	<p>#inclusive : Participation using twitter and youtube</p> <p>Enjoying #virtualattendance via twitter Participants adding external evidence Engaging participants both inside and outside of the room Use of youtube for films of presenters – acknowledge by the organisation.</p>	<p>Fun and safe environment for learning</p> <p>– Language risk, suboptimal outcomes Learning observing understanding disability – ACC improve health where I work Simulated Hospital admissions @canterbury Safe environment to share complex and challenging information – mortality, sepsis – college course could be publicised more widely → using hospital passports Simulation hospital admissions – Atmosphere Can health be fun Nursing/health focused Slowie – medical model → social model → equality/equity model of disability – LD is a protected characteristic</p>
<p>Whole system workforce questions</p> <p>how much input on Id do healthcare student get on their courses? a lot to think about, time to reflect How do we facilitate learning about needs of people with learning disabilities across all our professions? How can we best prepare healthcare staff to make best interest decisions appropriately? Availability of Id training for social care staff? Healthcare training for social care staff needs addressing improve care for pwld?</p>	<p>Inclusive – Experts by Experience</p> <p>we should get SU more involved in planning courses at BCU Pwld should have the same job opportunities as everyone else Overall Observation antenatal → children and families, education, equality, emotion and mortality passionate and funny advocate. NHS to be a model employer of pwld Hayley & sally (LOUD)</p>	

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<p>High degree of staff untrained in interpreting and managing behaviour? Is there appetite for joint social care /healthcare modules? What support do trainee dr's have? anything similar elsewhere? 90% of women who have positive test for down's syndrome have a termination Building the right support' report reference Developing models that reach across the whole system 50% reduction of pwld in atu's by 2020 Collaboration & innovation, creativity, team work Finding routes – navigators HEE – compassion and care based recruitment future of training for health and social care staff we should get SU more involved in planning courses at BCU</p>	<p>Scott Inclusive – experts, trainer, not service users! Bright futures LOUD – involving pwld involving pwld Keynotes 1) pwld parents 2) professionals</p>	
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KSS Learning Disability Community of Practice: Conference evaluation 2016

Appendix 2 Table showing words written in the One Word Evaluation exercise

Inspiring x 10	Fabulous x3	Amazing x2	Informative x2
Humbled x2	Thought provoking x2	Mind blowing x2	Empowering x2
Engaging x2	Awesome x2	Conversations x2	Moving x2
Phenomenal	Transitions	Thrillingly promising	Innovative
Creative	Reinvigorating	Welcome	Thought provoking
Brilliant	Liberating	Mixed	Powerful
Scott	Enlightening	Emotional	Real
Enjoyable	Great work		Super
Keep learning, Keep smiling, Enjoy – signed Vanessa.			

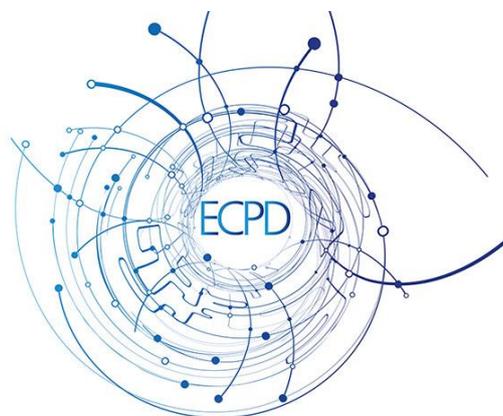
Appendix 3 Free text data from Post Conference Evaluations

Inspiring, thought provoking, refreshing, emotional, motivating, interesting love, ideas, (speakers) powerful and emotional energising	Latest developments, gaining understanding, regional and strategic perspectives, share ideas and innovations learnt new things,
People friends connections, contacts including environment, choice, networking, experts by experience, inclusion, variety	Areas for development 1) conference themes not entirely articulated through presentation 2) involving pml 3) more time for collaborative action

Appendix 4 Secondary Integrated analysis of data sources

<p>Participants Inspirations, emotions, humanity and learning</p> <p>Inspiring, thought provoking, refreshing, emotional, motivating, interesting love, ideas, (speakers) powerful and emotional energising</p> <p>Empowering x2 Amazing x2 Inspiring x10 Super Fabulous x3 Thought provoking x3 Phenomenal Emotional Awesome x2Enlightening Humbled x2 Thrillingly promising</p> <p>Brilliant Liberating Mind blowing x2 Powerful Welcome</p> <p>Moving x2 Engaging x2</p>	<p>Inclusive innovative learning involving experts by experience and information technology.</p> <p>#inclusive : Participation using twitter and youtube Inclusive – Experts by Experience</p> <p>Latest developments, gaining understanding, regional and strategic perspectives, share ideas and innovations learnt new things, experts by experience</p> <p>Informative x2 Transitions Scott Innovative</p>	<p>Whole system workforce network questions</p> <p>People friends connections, contacts including environment, choice, networking, , inclusion, variety</p>	<p>Fun and safe environment for learning</p> <p>Creative Reinvigorating Real Enjoyable Great work Conversations x2</p>
<p>Areas for development 1) conference themes not entirely articulated through presentation 2) involving pmlD 3) more time for collaborative action Mixed</p>		<p>Keep learning, Keep smiling, Enjoy – signed Vanessa.</p>	

**The KSSLDCoP is a fellow
of the England Centre for
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**They are support by
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