



Healthy, Safe and Fulfilled Lives:

Kent Surrey Sussex Learning Disability  
Community of Practice Refresh 2020





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[www.ldcop.org.uk](http://www.ldcop.org.uk)

[info@ldcop.org.uk](mailto:info@ldcop.org.uk)



[@ksslldcop](https://twitter.com/ksslldcop)



[Kent Surrey Sussex Learning Disability Community of Practice](https://www.facebook.com/KentSurreySussexLearningDisabilityCommunityofPractice)

Authored on behalf of the Kent Surrey Sussex Learning Disability Community of Practice by  
Daniel Marsden, Bob Parsons, Jonathan Coady-Mayall and Tracey Eyles.



## Easy to Read Kent Surrey Sussex Learning Disability Community of Practice Refresh Report



Bob Parsons, Jonathan Coady-Mayall and Daniel Marsden took the leadership of the Kent Surrey Sussex Learning Disability Community of Practice in June 2020.



In September we asked people from Kent Surrey and Sussex about the Community of Practice.



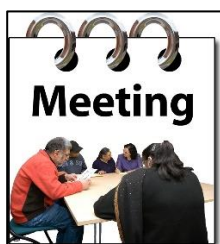
People said the Community should work with people with learning disabilities and their allies to live Healthy, Safe, and Fulfilled Lives.



The Community will start to look for opportunities for work to help people live healthy safe fulfilled lives



The Community will organise regular online meetings to learn and meet community members.

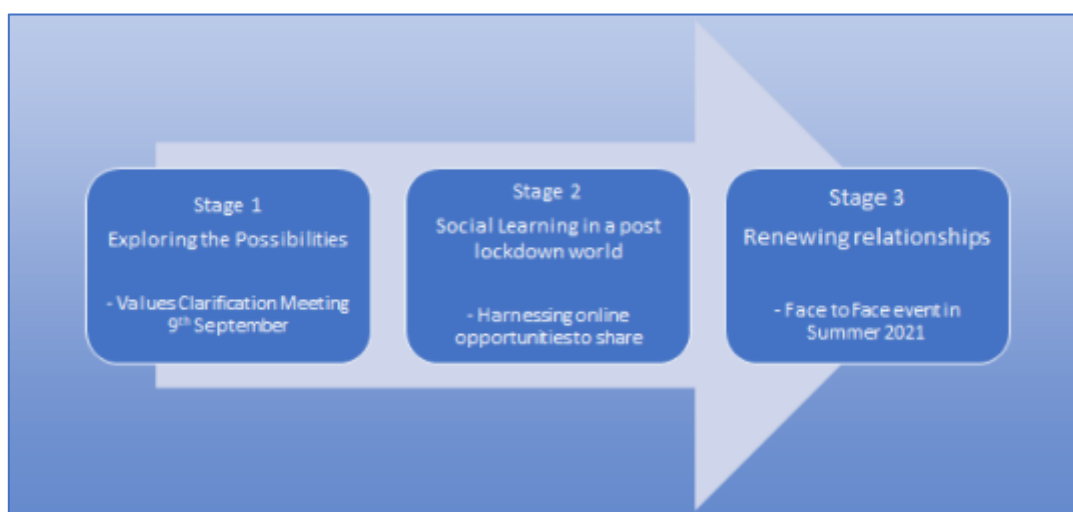


The Community's Steering group will be looking for more people to get involved.

## Introduction

In June 2020 BILD handed the Kent Surrey Sussex Learning Disability Community of Practice back to the local community. Three members - Bob Parsons, Jonathan Coady-Mayall and Daniel Marsden (Kent Surrey Sussex Learning Disability Community of Practice, 2020, KSSLDCOP) - received the Community's archive of the website, social media and mailing list.

A three-stage strategy was developed to refresh the Community, to establish our shared purpose, organise some social learning events, and plan for a time when face to face events might be possible.



*Figure 1 Three stage strategy for refreshing the Community*

The first stage of the strategy was an online workshop with 25 representatives from across the region, including health and social care professionals, academics and family carers and an online survey for those that were unable to attend.

This paper reports on this first stage of refreshing the community, utilising participants contributions to outline the Community Shared Purpose, how this will be achieved, and identify how we can all contribute to the Community's evolution.

## Context

The Kent and Medway Learning Disability Community of Practice was established in May 2013 with support from East Kent Hospital NHS Foundation Trust and England Centre for Practice Development at Canterbury Christchurch University. After three successful annual conferences Health Education England (HEE) funded the community to grow to a region wide coverage in 2016.

In 2017 HEE further supported the Community to explore opportunities to become self-sustaining and BILD oversaw this project. BILD's evaluation (2020) reports on work from April 2017 – April 2019 which aimed to develop leadership through a series of localised meetings. However, the financial stability of the community remained a challenge, with three models of development considered, being membership, sponsorship and grant funding.



While the BILD (2020) evaluation indicates the requirement for the Community of Practice to be best realised through face to face activity, the implications of Coronavirus in 2020 has meant any plans for this type of work has had to be suspended, with no obvious resolution in sight. It is believed that video conferencing software such as Zoom and Teams can provide a viable alternative, and due to increased use of such technologies to access healthcare, social activities and friends and family many will have become more comfortable with this technology.

## Process

An online workshop for 25 people was held on 9<sup>th</sup> September 2020 with a subsequent online survey being made available from this date until 30<sup>th</sup> September 2020; this was completed by 13 respondents.

A values clarification exercise (Warfield & Manley, 1990) provided the basis for most questions in both workshop and survey. These included reference to:

- the ultimate purpose of the Community of Practice (CoP)
- how the purpose could be achieved
- the enablers and inhibitors; and
- what the priority steps should be.

These were added to by questions about valued community activity, the Community name, the accessibility of Community activity, and further involvement in the Community.

## The draft purpose and how it will be achieved

The Community of Practice covers the Kent, Surrey and Sussex region, and is concerned with people with learning disabilities.

The **Ultimate Purpose of the Community of Practice** is to enable people with learning disabilities to live healthy, safe and fulfilled lives.

The purpose of the Community is to empower and enable health, care and education professionals, and allies to work in partnership with people with learning disabilities and their families to:

- 1) define and eradicate inequalities in health and wellbeing;
- 2) implement standards and share good practice; and
- 3) enable person centred social inclusion.

**This purpose will be achieved through** turbo charging engagement and empowerment - a community of energy and drive that supports each other, being clear about the community purpose, methods and actions to develop the Kent, Surrey and Sussex Community through collaborative opportunities and projects by:

- bringing people together and working collaboratively;
- sharing information;
- empowering people with LD to be heard;



- sharing best practice;
- sharing experiences;
- having a set agenda agreed for each meeting by creating a platform for ideas to be shared for each agenda (possibly using polls?);
- Quality Improvement philosophy;
- talking and acting;
- virtual meetings, webinars, face to face events (when safe to do so) and working in partnership;
- research, innovation, influencing policy and publishing
- devoting time to its ongoing development.

### Priority Actions for the Community

- 1) Organise regular meetings, webinars and events
- 2) Reengage with people with learning disabilities, their families and other audiences
- 3) Developing new projects addressing local and national needs and priorities
- 4) Build on the shared purpose to establish the CoP as a recognised voice for people who face inequality and discrimination.

### Enablers and Inhibitors

1. Social distance – creating connections to realise shared goals
2. Creativity in partnership working and sharing resources.
3. Simplified communication, understanding engagement and accessibility

### Survey results

Figure 2 indicates the three most significant elements of value the Community can provide will be:-

- a. the exchange of ideas,
- b. an opportunity to network,
- c. understand the concerns of people with learning disabilities.

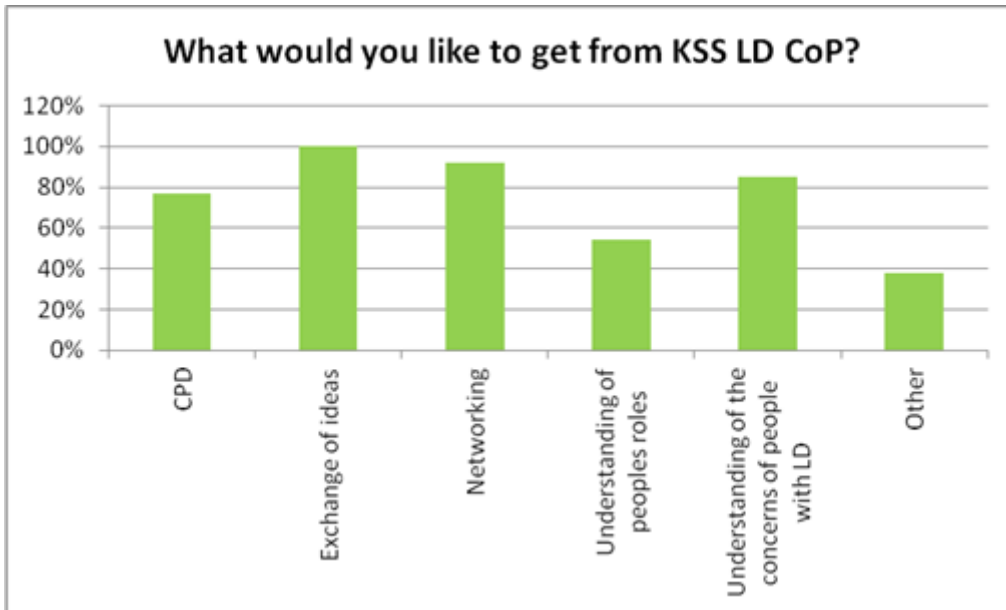


Figure 2 Survey Question 1

Figure 3 shows the name “Kent Surrey Sussex Learning Disability Community of Practice” is okay, although it was acknowledged that it could be more understandable for all.

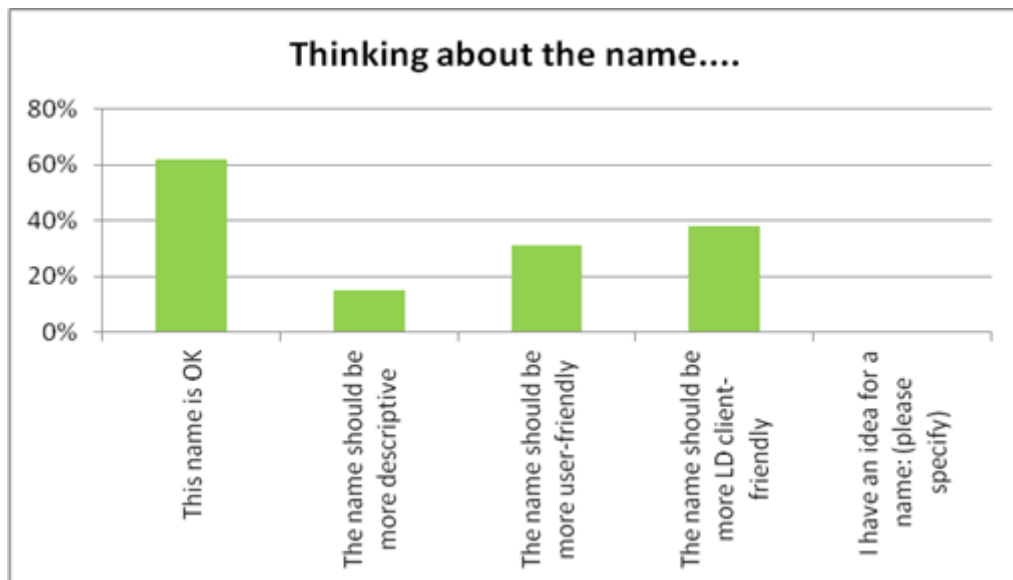


Figure 3 Survey Question 2

Figure 4 indicates that when face to face events became available, they would prefer these to be closer to home if possible, with enough parking or on a public transport route. It was also clear from this question only a small percentage would choose not to attend.

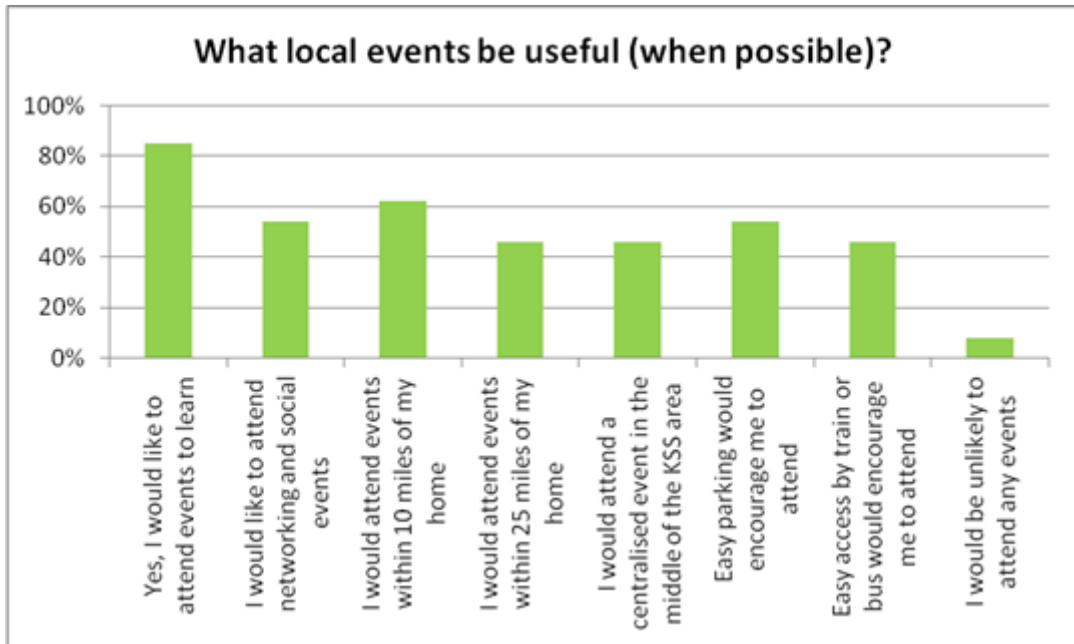


Figure 4 Survey Question 3

Figure 5 evidence that all respondents would attend online Learning events, with half indicating a preference for afternoon events and a third advocating for evening events.

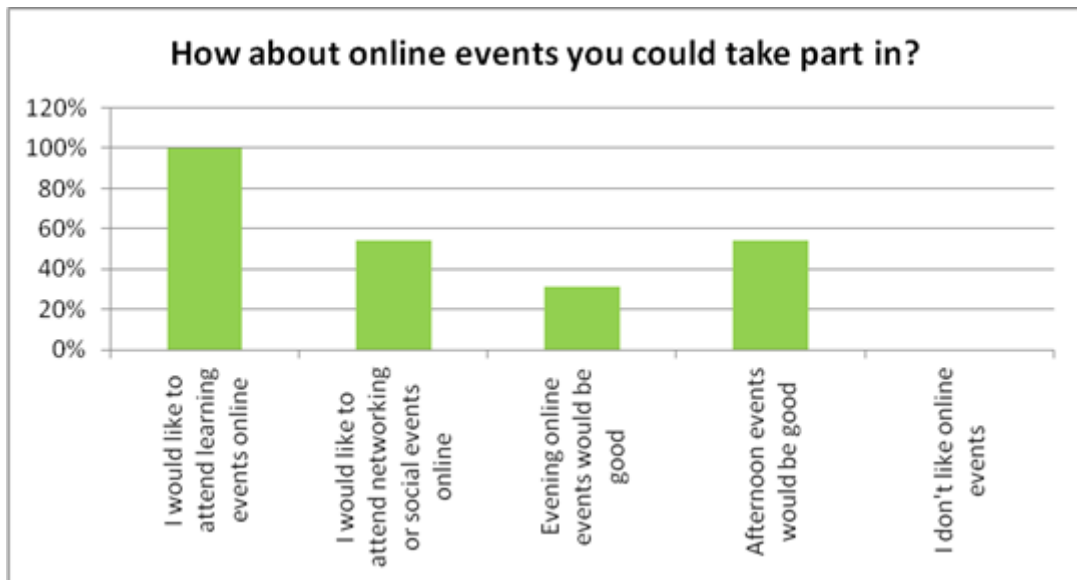


Figure 5 Survey question 4





## Reflections and next steps

This report has sought to synthesise feedback from the Community as a first part of refreshing and centring the Community in the Kent Surrey Sussex region. It has confirmed the Community name and its focus on the health and wellbeing of people with learning disabilities and those that have an interest in this population. The shared purpose of the Community is to support people to live healthy, safe and fulfilled lives, with a focus on the identification and eradication of inequalities in health and wellbeing, to implement and share good practice, and enable person centred social inclusion.

It is acknowledged that experts by experience have been central to the Community since its inception and this will remain the case. However, both the BILD Evaluation and this report indicate that while social distancing remains a requirement, a new model for engagement and involvement is required. As such, the Steering group wishes to explore new engagement models as a priority, with people with learning disabilities and partner organisations and are keen to review and rate the Community activity in this regard.

Feedback also indicates that plans for regular online meetings, webinars and events linked to the Community shared purpose and value of inclusivity would be beneficial to support the next phase of the Community, to this end several partners have offered projects that are aligned with the Community shared purpose to present in the next stage of the strategy.

It has also been recognised that along with providing a platform for sharing good practice the Community ought to be working on the development of new projects that can address local and national priorities. Consequently, the Community has contributed to an HEE tender submission and is considering the possibilities for developing a project to develop local facilitative leadership to develop practice, innovation, and culture through practice development. To achieve this, strategic partnerships will be sought across the region and beyond to better influence practice, education and research.

To enable this activity, the Community requires a firm foundation and -according to the previous evaluation (BILD, 2020)- a significant investment in resources. The Community Steering group will require development, offering structured opportunities to those that may wish to contribute particularly in the areas of web editing, finance, practice and community development, research and project management.

Widening the knowledge, skills and experiences of the Community Steering group will also provide opportunities to confront the challenges posed by the Community becoming self-sustaining. Financially the Community has a small annual outgoing for web space pertaining for the blog and its archive, as such opportunities for income generation to maintain and develop the Community resources will be explored.

This initial activity to refresh the Community shared purpose has had significant limitations associated with purposive engagement and involvement from relevant stakeholders. These results, interpretations and plans provide a basis for the next stage of activity, re-establishing the social learning aspects of the Community. Through these facilitated events, further work will be undertaken to review and develop these plans and to update the strategy.



## Conclusions

This paper has sought to acknowledge the transfer of the Community, to re-establish a shared purpose based on the Community's contributions via an online workshop and survey.

This is a new phase for the Community working with people with learning disabilities and their allies to live healthy safe and fulfilled lives, through identifying and eradicating inequalities in health and wellbeing.

The Community requires a solid foundation with which to develop, and the first activities will be to develop an inclusive steering group and a series of online social learning events, with further plans for facilitating learning and networking, while also identifying opportunities to develop new knowledge, leadership and skills to attain the above purpose.



## References

BILD (2020) Kent, Surrey and Sussex and Greater London, Learning Disability Communities of Practice Evaluation Report. Available online at <https://idhekss.wordpress.com/reports/a-z/#COP> Last accessed 18<sup>th</sup> October 2020.

Kent Surrey Sussex Learning Disability Community of Practice (2020) Your New Steering Group. Available online at <https://ldcop.org.uk/your-new-steering-group> Last Accessed 18th October 2020

Warfield, C. and Manley, K. (1990) Developing a new philosophy in the NDU. Nursing Standard. Vol. 4. No. 41. pp 27-30.

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 18<sup>th</sup> October 2020.



## Appendix 1 Meeting & Survey Themed Results

|  | Theme   | Evidence extracted from workshop & survey   |
|--|---|---|
| <p>We believe the ultimate purpose of the community is:-</p> | <p>1) To nurture inclusion, participation and innovation through promoting best practice and setting standards.</p> | <ul style="list-style-type: none"> <li>• Sharing best practice learning lessons</li> <li>• To connect people, services and information sharing</li> <li>• To work together in partnership with Organisations to innovate</li> <li>• To provide networking opportunities</li> <li>• To bring together, share, and develop through active participation</li> <li>• To bring people together</li> <li>• Networking. Share best practice. Peer support. Promote local events</li> <li>• To promote the exchange of good practice</li> <li>• To nurture, support and accept everyone</li> <li>• Gain perspective and advice from others based on barriers and challenges within learning disabilities. Support one another and share learning</li> <li>• Learning lessons</li> <li>• To raise standards of support for people who have a learning disability through sharing good practice and relevant information.</li> <li>• Sharing information, support and services for local people with learning disabilities.</li> <li>• Establishing a community based online group</li> </ul> |



|  |   |  |
|--|---|--|
|  |   | <ul style="list-style-type: none"> <li>• Enhance practice and foster a community that supports vulnerable people and the systems around them</li> <li>• Connect people working in the interests of people with learning disabilities</li> <li>• To provide a space to learn from others so that I can do my job better and in turn improve the health and care experience &amp; outcomes for people and families</li> <li>• Sharing good practice including people with learning difficulties as they are the experts by experience</li> <li>• To be a person centred accessible and inclusive community</li> <li>• Sharing best practice, involving people with lived experiences, creating a culture of openness and honesty across all KSS organisations and communities</li> </ul> |
|  | <p>2) Eradicating inequality and enabling people with learning disabilities to live safe healthy, fulfilled and enriched lives.</p> | <ul style="list-style-type: none"> <li>• Enriching lives</li> <li>• Ensure people with Learning disability have the same access to choice through reasonable adjustments in their everyday life as the wider community</li> <li>• Raise awareness of Learning Disability and be inclusive</li> <li>• "eradication of health inequalities"</li> <li>• Who can create positive change</li> <li>• Support people and their families to be part of the community and have equal rights</li> </ul>  |



|   |  |   |
|---|--|---|
|   |  | <ul style="list-style-type: none"> <li>• To support people with learning disabilities and autism to live safe healthy fulfilled lives</li> <li>• Making services better for learning disabilities by making sure there is enough information about correct medicines for future diseases</li> </ul>   |
| <p>We believe this purpose can be achieved by:-</p> | <p>1) Turbo charge engagement and empowerment - a community of energy and drive that supports each other</p> | <ul style="list-style-type: none"> <li>• Bringing people together, including those who have a learning challenge</li> <li>• Working collaboratively</li> <li>• Networking. Peer support. Promoting local events</li> <li>• The energy and drive we bring together to reduce health inequalities</li> <li>• Honest, collaborative working</li> <li>• To share information and network with people</li> <li>• Empower people with LD to be heard and turbo charge the influence this has</li> <li>• To work together to better serve people with learning disabilities and autistic people in KSS.</li> <li>• To share and learn from one another</li> <li>• Members of the CoP committing to the aims and outcomes</li> <li>• Having more people actively engaged in the component parts of the COP. Stronger together</li> <li>• Awareness raising and working together</li> <li>• Empower people to live healthy and fulfilling lives to their best ability</li> <li>• Sharing best practice. Sharing experiences</li> </ul> |



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|  | 2) Being clear about the community purpose, methods and actions              | <ul style="list-style-type: none"> <li>• Having a set agenda agreed for each meeting with the opportunity to contribute to discussion points or particular trends. Possibly create a platform for ideas to be shared for each agenda (possibly using polls?)</li> <li>• QI philosophy?</li> <li>• Talking AND acting. In the video Daniel said there had already been a lot of 'identifying the issues' - to make a difference the community will need to take action</li> <li>• research, innovation, influencing policy and publishing</li> <li>• Virtual meetings. webinars. face to face events (when safe to do so) and working in partnership</li> </ul> |
|  | 3) Developing the Community through collaborative opportunities and projects | <ul style="list-style-type: none"> <li>• Seeking out collaborative opportunities and projects to support development, transformation ensuring we stay true to our values and ultimate purpose</li> <li>• Devoting time to its ongoing development</li> <li>• To share evidence-based research and best practice knowledge where there is no formal evidence base as yet</li> </ul>   |
| We believe the priority actions to achieve the purpose are:- | 1) Organise regular meetings, webinars and events                            | <ul style="list-style-type: none"> <li>• Setting objective aims and outcomes for each event</li> <li>• To organise online meetings at intervals throughout the next year, perhaps set up a Facebook group to keep discussion going</li> </ul>  |

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|  |   | <ul style="list-style-type: none"> <li>• Think about setting up webinars on different subjects to keep people up to date</li> <li>• Allowing people to share a mix of content that you feel will be beneficial for the group users, encouraging conversation and support where possible and ensuring accessibility to all. Building a consistent network of people to use the group, ensuring content is relevant and current</li> <li>• Conferences</li> </ul>   |
|  | <p>2) Re-engage with people with learning disabilities, their families and other audiences.</p> | <ul style="list-style-type: none"> <li>• Start to re-engage with people with learning disabilities, family carers and those in health, and social care and the third sector to enable all to shape the future direction</li> <li>• Think of the audience for each event how can we reach out to families?</li> <li>• Involving people with learning difficulties as part of the steering groups to see through their eyes first can often be the best way forward</li> <li>• Bringing together professionals in Health, Caring, and Education, with people who actually have learning disabilities and their parents and carers</li> <li>• Professional engagement, networking, CPD and working within an evidence based framework to evaluate change</li> <li>• Collaboration, action at senior decision makers level</li> </ul> |





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|  |   | <ul style="list-style-type: none"> <li>• Simple engagement of like-minded groups and individuals in an easy and accessible way to allow easy flow of knowledge</li> <li>• Not focusing on too much at one time. Get the community to identify a campaign then hit it hard. Make sure the Learning Disability Partnership Boards are all linked in</li> </ul>   |
|  | 3) Developing new projects addressing local and national needs and priorities.  | <ul style="list-style-type: none"> <li>• A common aim which all parties can strive achieve</li> <li>• Understand system priorities within organisations locally and nationally; create a delivery plan to begin to address needs and match these to individual priorities</li> <li>• To start any new project</li> <li>• Identifying and addressing local health inequalities</li> <li>• Providing opportunities for people to join up and work on different issues that are important to and affect the lives of people with learning disabilities and their families</li> <li>• Sharing information with peers and publishing the information</li> <li>• First checking the medicine will protect them from whatever virus and first find out what the effects might do to patients</li> </ul> |
|  | 4) Build on the shared purpose to establish the CoP as a recognised voice with people who face inequality and discrimination. | <ul style="list-style-type: none"> <li>• To build on previous work and to refresh by looking to the future ensuring that the C of P has a platform to work from</li> </ul>   |



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|---|--|---|
|   |  | <ul style="list-style-type: none"> <li>• Maintain the momentum created to ensure the success of the CoP. Become a recognised voice for people who face inequality and discrimination</li> <li>• Working collaboratively, with a single shared purpose, common agreed operating values &amp; principles, regular connection &amp; collective shared intelligence</li> <li>• Working in co-production- having people with learning disabilities at the centre of the work with a strategic and planning role. By finding ways to meaningfully connect with one another. By seeking to understand as a COP what is working/not working and continuously improving</li> </ul> |
| <p>We believe the factors that enable/inhibit the purpose to be achieved include...</p> | <p>1. Social Distance – creating connections to realise shared goals</p> | <ul style="list-style-type: none"> <li>• Social distancing Travel</li> <li>• A lack of opportunity for informal contact between services and people with learning disabilities and their families. Few opportunities to work together on specific goals</li> <li>• Inhibited by - social distancing, lack of clear aims and group cohesiveness</li> <li>• Not feeling personally connected to the COP, only intermittent connectivity</li> <li>• Inhibiting the purpose will be the challenge of engaging those professionals to listen to the needs of the people they serve</li> </ul>  |



|  |  |  |
|--|--|--|
|  | <p>2. Creativity in partnership working and sharing resources.</p>             | <ul style="list-style-type: none"> <li>• ...funding</li> <li>• Big aim, with lots out of our hands - lack of funding, wider social inequalities, Conservative government...</li> <li>• Lack of funding for the COP. Busy working and home lives. Active Members, Organisations included, consistent system for feed and postings</li> <li>• It is important that people be acknowledged for their work publicly and possibly financially if that is possible</li> <li>• Defensive practice preventing creativity. Partnerships do not happen between organisations they are between people speed date the professionals</li> </ul> |
|  | <p>3. Simplified communication, understanding engagement and accessibility</p> | <ul style="list-style-type: none"> <li>• To enable - good communication and shared vision</li> <li>• Perception, lack of understanding</li> <li>• Diverse and wider engagement, for what is shared to address current challenges and needs i.e. serve a purpose</li> <li>• Lack of ownership, onerous rather than accessible access; not relevant</li> <li>• Accessibility, length of time, regularity of meets, &amp; sharing progress/communicating regularly between meets</li> <li>• Look at past leaflets and how we can make them more simple</li> </ul>   |