

Draft Summary
**Launch of Community of Practice (Learning Disabilities) Workshop
involving practitioners, people with learning disabilities, their carers
and other stakeholders**

May 2013

1. Introduction

The workshop was held to launch a community of practice (CoP) across the South East that broadly aims to support professionals caring for and working with people with learning disabilities. In the spirit of partnership, people with learning disabilities, their families and carers and other related stakeholders were also invited to attend.

2. Workshop Process

Participants contributed to workshop activity that fell into two phases. *Phase 1* involved participants using a values clarification exercise to explore values and beliefs held about the following:

- The ultimate purpose of the Community of Practice (CoP)
- How the purpose could be achieved
- The enablers and inhibitors
- What the CoP would look like
- What the priority steps should be
- What the individuals responsibility is to the CoP
- IT tools to assist CoP

A parallel workshop was held with people with learning disabilities to explore the question: "If you were sick, how would you like to be cared for in hospital?"

Phase 2 involved participants using data from phase 1 to:

- develop a purpose of the CoP statement
- identify strategic objectives
- identify priority actions

Parallel discussion took place with participants with learning disabilities and focused on answering the question:

"What is the most important thing for the Community of Practice to do first?"

The full detail of the contributions made by participants and subsequent theming for phase 1 is included in Appendix 1, and Phase 2 in Appendix 2

3. Draft Purpose of the CoP and how this will be achieved

The **ultimate purpose of health care for people with learning disabilities** is to improve health, save lives and reduce health inequalities

The **purpose of the community of practice (CoP)** is to support carers, care workers and professionals to work together with people with learning disabilities and their families to:

- uphold the principles of person-centred care and transparency
- implement standards and best practice
- improve equality and access

This purpose will be achieved through creating a community of support based on partnerships with people with learning disabilities and other key stakeholders that is collaborative, inclusive and participative, towards the common goals above by:

- raising awareness, sharing information, learning and networking
- sharing good practice, experiences and expertise
- developing better metrics and researching
- growing practice leaders and professionals
- addressing institutional inhibitors and discrimination
- campaigning, advocating and promoting the needs of people with learning disabilities

4. What people with learning disabilities want

People with learning disabilities experiencing healthcare want health care professionals to:

- Be nice to me, treat me with dignity and respect and talk to me as a person
- Tell me what is happening simply so I am not frightened, and tell my family
- Use simple language and pictures, listen, and give me help and time to understand, this may sometimes require a longer appointment
- Give me easy read information on health problems
- Make sure I am not in pain
- Ask me what I like to eat and drink
- Help me by getting to know me and what I can do for myself, knowing and understanding my disability
- Let me have people I know with me to talk to nurses and doctors
- Make me feel better and give me the right treatments
- Let me first look around the place and then I don't mind going to hospital
- Understand what worries, hurts and frightens me

5. Individual Responsibilities as members of the community of practice

To enable the CoP to be successful will require individual members to:

- Tell people about the CoP and feedback to colleagues and organisation
- Challenge poor practice and raise awareness
- Open to learning and reflection and listening to each other
- Make it happen by participating, working together and taking responsibility

6. IT tools to support the CoP

Whilst many tools for supporting virtual participation in the CoP were identified, others also wanted a chance to meet face to face and to hold events. The tools identified included: Twitter; Email; Integrated IT Web/Social Networking flogs/Forum pages; Events, mails, easy read webex; and Skype

7. What would be happening in the CoP if it was successful?

Table 1 identifies the activities taking place if the CoP is successful as well as identifying the enabling factors and consequences

8. Priorities in establishing the Community of Practice

These fall into areas that relate to four themes:

- Helping people with Learning disabilities to know what to expect
- Raising awareness for frontline staff about the needs of people with leaning disabilities and a way of sharing best practice
- Exploring how the CoP can monitor its effectiveness
- Influencing organisations, commissioning and governments

Table 1: What would be happening (the attributes) in the CoP if it is successful as well as the key enabling factors and consequences?

ENABLING FACTORS	ATTRIBUTES	CONSEQUENCES
<p>Individual members are:</p> <ul style="list-style-type: none"> • passionate • open to learning and reflection and listening to each other • willing to participate, work together and take responsibility <p>Institutional support:</p> <ul style="list-style-type: none"> • Enables members to participate 	<ul style="list-style-type: none"> • Person-centred collaborative partnerships involving all • Meetings that are both face to face and virtual • Sharing knowledge and expertise, resolving problems that are relevant and informative • Helping each other to challenge poor practice and raise awareness • Learning and reflecting and listening to each • Members telling people about the CoP and feedback to colleagues and organisation networking, 	<p>Individuals:</p> <ul style="list-style-type: none"> • Members feel accepted, included protected, safe and empowered • Frontline practice is based on best practice and continuously improved through demonstrable metrics • People with learning Disabilities experience care that is person centred and meets their needs based on best practice <p>Community of Practice</p> <ul style="list-style-type: none"> • Has growing membership • Is externally connected with a high profile <p>Health Organisations</p> <ul style="list-style-type: none"> • Reduced discrimination • Improvement in health outcomes fro people with learning disabilities <p>Society</p> <ul style="list-style-type: none"> • Improvements in health equality and access

9. Evaluation of workshop

The following words were identified as describing the experience of the workshop participants:

- Inspiring
- Good networking
- Challenging
- Thought provoking
- Very interesting
- Listening to opinions
- Good that people know what we want to say
- Box-ticking

These words were used to develop a Haiku to capture both the evaluation and the experience:

“Listen, opinions
Thought provoking, box-ticking
What we want to say”

Appendix 1

Phase 1 of Workshop

Data and analysis

A values clarification exercise was held with participants to explore values and beliefs held about the following:

- The ultimate purpose of the Community of Practice (CoP)
- How the purpose could be achieved
- The enablers and inhibitors
- What the CoP would look like
- What the priority steps should be
- What the individuals responsibility is to the CoP
- IT tools to assist CoP

A parallel workshop was held with People with Learning Disabilities to explore the question:

“If you were sick, how would you like to be cared for in hospital?”

1. VALUES CLARIFICATION DATA

Text in red are suggested embellishments in theme titles to reflect the content of all the post-its in the theme more strongly.

Ultimate Purpose of the community of practice:

THEMES	INDIVIDUAL POST-ITS
Improving health, saving lives, reducing health inequalities:	<ul style="list-style-type: none">• Improving health• Reduce avoidable death• Reduce health inequalities through multi-agency working• Improve diagnosis and death• Reduce health inequalities for people with LD• Save lives• Reduce health inequalities• Referral other health professionals Health OT, SALT, Physio
Raising awareness, networking, Communicating, sharing information and supporting frontline	<ul style="list-style-type: none">• Awareness raising• Share information• Network and communicate• Communication and awareness tool• Learn• Health professionals having understanding of LD• Share

	<ul style="list-style-type: none"> • Front line support • Engage family of nursing • Support
Standards, improves equality, access and researches and provides good practice:	<ul style="list-style-type: none"> • Fair and equal practice • within healthcare for people with LD • Improve equality • Regulate practitioners • Research • Set standards • Performance indicators • Take action • Good practice • Policy – procedure • Access • Equal rights
Campaigning, advocating and promoting	<ul style="list-style-type: none"> • Campaigning x2 • Promote and advocacy • Promote issues • COP needs teeth! (and use them)
Useable and understandable	<ul style="list-style-type: none"> • Useable – understandable • To find out where I fit in and what I can do • Understandable terms of reference
Upholds person-centred care and transparency	<ul style="list-style-type: none"> • Individual person centred care • Treat all people with respect, maintain dignity. • Be patient. • Human rights • Awareness of an individual capacity • Empathy • Need to be transparent

How the purpose above can be achieved:

Communicating, partnership and creating a community of support:	<p>Networking Listening Partnership Communication and action results Networking Communication and partnership Collaboration Community of support People with learning disability to contribute and drive the COP Listening to families, carers and people with LD or representatives</p>
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Being clear about purpose and having a common goal:	<ul style="list-style-type: none"> • Being clear about what needs to be done • Being clear about vision • Common goal • Core values and beliefs e.g. white paper
Sharing good practice, experiences and expertise:	<ul style="list-style-type: none"> • Good practice • Experts • Experience • Sharing • Sharing experiences • Experience • Sharing good practice • Expertise – stakeholders
Leadership and professionalism	<ul style="list-style-type: none"> • Lead by example • Leaders • Professionalism • Culture
Money and funding:	<ul style="list-style-type: none"> • Government banking • Money, money, money • Funding for staff/carers to remain in hospital with LD • Properly funded services
Learning, education and training and raising awareness	<ul style="list-style-type: none"> • Raise awareness • Education • Mandatory training for all • Training • Improvement in training for health professionals to recognise LD as a separate from medical diagnosis • Education and training • Improving training and awareness for health professionals. • Demonstrating • Lessons learnt exercise • Seminars
Better metrics	<ul style="list-style-type: none"> • Better metrics
It says it all – Random	<i>We're unsure how this theme was intended to be used.</i>

Inhibitors to achieving the CoP's purpose:

Ignorance, lack of awareness and discrimination:	<ul style="list-style-type: none"> • Ignorance • Discrimination • Lack of awareness • Narrow approach to target audience
Resource	<ul style="list-style-type: none"> • Caseload • More LD nurses in hospitals

	<ul style="list-style-type: none"> • Lack of trained staff available • Lack of resources • Spending cuts
Institutional:	<ul style="list-style-type: none"> • Organisation campaigns e.g. Mencap • Legislation • NHS and current changes • Organisational buying
Not listening and poor communication:	<ul style="list-style-type: none"> • Poor communication • Experts believing they have all the answers and not listening • Poor can inhibit

Enablers to achieving the CoP's purpose:

Communication:	<ul style="list-style-type: none"> • Drivers and motivators • Assessment • Broaden approach • Longer appointments. Use of language, mode mobile and level • Media • Understanding • Enquiry reports • Good can enable • Listening to representative forums • Easy read documents available in line with tech B more available • Leaders who can communicate through various media.
Resources:	<ul style="list-style-type: none"> • Finance • Money and time • Trainee staff • Resource availability – knowledge and skills
Skills – Expertise:	<ul style="list-style-type: none"> • Both E & I Education • SALT that are LD trained • Knowledge and experience of practitioners • LD nurse recommendations are put into practice by ward doctors/nurses.
Institutional support	<ul style="list-style-type: none"> • Institutional support

COP Will Feel Like/Look Like

Meetings, sharing knowledge, resolving problems	<ul style="list-style-type: none"> • Support • Meetings • Examples • Knowledge and sharing
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	<ul style="list-style-type: none"> • Expose problems • Resolve problems • Meeting and resolving problems
Relevant, informative, passionate	<ul style="list-style-type: none"> • Relevant and informative • Dynamic • Passionate
Externally connected, networking, high profile	<ul style="list-style-type: none"> • A network • Successful • International • Connected externally • High profile with passionate people • High profile
Members feel accepted, included protected, safe and empowered	<ul style="list-style-type: none"> • Accepted • Valued – easy to understand • Protection • Inclusive • Inclusion • Do stuff and feel comfortable, related • Empowering, comfortable, individualised, standard, equal, inclusive • Safe • Accepted safe, included, protected
Person-centred collaborative partnerships involving all	<ul style="list-style-type: none"> • A proper partnership with people with LD • To involve frontline health practitioners from the beginning – a partnership • Person centred • Multidisciplinary • Should feel like a partnership, involving everyone at all levels • Joined up • Seamless • Collaboration – working together • Inclusion of family, nursing and medics • Only co-production with people with LD and/or carers will NOT work

Priority Steps

Influencing GP, government & Legislation:	<ul style="list-style-type: none"> • Influencing government • Focus on 'sign up' for charters • Board sign up • Legislation • More awareness from government down within the country • GP & health across the board to increase communication &
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Funding	<ul style="list-style-type: none"> • Finance • Funding/sponsorship
Inclusion, involvement, partnership:	<ul style="list-style-type: none"> • For all organisations to make a commitment • Involvement • Inclusion • Feedback from service users • Inclusion and partnership “Make it meaningful”! • Inclusion
Raising awareness and cultural change:	<ul style="list-style-type: none"> • Raising awareness • Promoting awareness of patient with LD • Culture needs to change • Culture at all levels needs to change • Extend beyond LD community
Communication:	<ul style="list-style-type: none"> • Communication and networking • To communicate more effectively • Clear communication • Communication • Choices for individuals to be in main ward or single room • communication, networking
Education, and service users delivering training together	<ul style="list-style-type: none"> • Education and training • Future dates across Kent • Education. • Service users delivering training • Listen to people with LD – 3 families to ensure programme set up they are service user B person centred. • Get together
Zero tolerance to bad practice	<ul style="list-style-type: none"> • Zero tolerance to bad practice
Publicising CoP	<ul style="list-style-type: none"> • Publicising

Individual Responsibility to CoP

Tell people about the CoP and feedback to colleagues and organisation:	<ul style="list-style-type: none"> • Feed information into the community • Tell people about us • Communicate and share • Vocalise our commitment and need to enable participation in a COP • Talk to others • Feedback to colleagues and organisation
Challenge poor practice and raise awareness	<ul style="list-style-type: none"> • Challenging poor practice • Challenge, raise awareness, challenge equality, change individuals mind set
Open to learning and	<ul style="list-style-type: none"> • Openness

reflection:	<ul style="list-style-type: none"> • To learn • To reflect
Make it happen by participating, doing, working together and taking responsibility:	<ul style="list-style-type: none"> • Follow up – not just lip service • Working together and taking responsibility • Make it happen • Participate • Commitment • Keep focus • Inclusion for all • To attend and participate
Listening	<ul style="list-style-type: none"> • Identify activity do not talk! • To listen

IT Tools to assist CoP

Twitter:	<ul style="list-style-type: none"> • Twitter and emails
Email:	<ul style="list-style-type: none"> • Email networks
Integrated IT Web/Social Networking flogs/Forum pages	<ul style="list-style-type: none"> • IT systems • Google calendar • Providing IT tools to do it • Blogs • Facebook • Linked-in • Forum page
Don't want virtual community:	<ul style="list-style-type: none"> • IT positives • IT negatives – we don't want a virtual community
Events, mails, easy read webex:	<ul style="list-style-type: none"> • Events • Mailshots • Facebook • Twitter • Emails • Easy read information
Innovation	<ul style="list-style-type: none"> • Innovation
Skype	<ul style="list-style-type: none"> • Skype
Ipads	<ul style="list-style-type: none"> • Ipads
Webex	<ul style="list-style-type: none"> • Webex

2. Workshop and Feedback from People with Learning Disabilities

Question considered:

“If you were sick, how would you like to be cared for in hospital?”

The words used by participants have been clustered to develop themes in the table below:

Themes from clustering similar words together	Words used by participants
To be nice to me, treat me with dignity and respect and talk to me as a person	<ul style="list-style-type: none"> • They should talk to the person and not the parent. • Find out how to treat people properly. • Respect and dignity. • I need people to be nice to me and kind, listen • To be nice • Talk to me, not my carer • Be nice – treat me with respect • Not to be shouted at • Respect my feelings • It was good – they asked me if I wanted the operation • Talk to me, not to my carers
Tell me what is happening simply so I am not frightened, and tell my family	<ul style="list-style-type: none"> • Tell me what is going to happen – so I’m not frightened • Tell you are trying to help • I’d like the doctors to tell my family I’m okay • To explain what is happening • Having someone to tell we are not well • I want the nurses to explain to me how they are going to – if I was scared, any easy suggestion. I want to know an easy way not to worry about operations • Tell me what’s happening – explain simply • They should say what’s wrong
Use simple language and pictures, listen, and give me help and time to understand	<ul style="list-style-type: none"> • Understand the language that is being used – no jargon or complicated words • I need simple words • I need pictures to help me • I need help for to talk to me • I need time to understand • What would help me is symbols, signing, pictures

	<ul style="list-style-type: none"> • Using easy words • Good at listening and understanding • Explaining simple • I need more time • Use easy words • Explain what is happening with short and coherent sentences • I would like pictures to help me to understand • For people to have patience whilst I'm talking • Respect and dignity. Be nice. Listen to me – not be rude or shout. • Be patient • Be good at listening and understanding me
Give me easy read information	<ul style="list-style-type: none"> • Accessible information like menus, hospital signs. Easy read appointment letters • Give me leaflets and information with pictures • Give me leaflets
Make sure I am not in pain	<ul style="list-style-type: none"> • Make sure that people are not in pain. • Some things hurt • Make sure I am not in pain
Ask me what I like to eat and drink	<ul style="list-style-type: none"> • What food you liked to eat. • Ask me what I like to drink and eat • Hot dinner, microwave meal • Hot dinner, good food • Ask me what I would like to eat and drink • Hot food that I like
Help me by knowing me	<ul style="list-style-type: none"> • Know about me and all my abilities • They should know I can't take tablets – medicine is okay
Let me have people with me I know to talk to nurses and doctors, I may need a longer appointment	<ul style="list-style-type: none"> • Carers/ parents to be able to stay up to 3 days • Need a carer • Let me have people I know with me (family or carer) • Help with talking to nurses and doctors • Need people who know us to help to talk to staff • Dad with me while in hospital – also Mum, family • Longer appointments
Make me feel better and the right treatments	<ul style="list-style-type: none"> • To make us feel better • I'd want the right treatments • Blood pressure • Blood test • Medicine and information • Good at injections • Keep the hands clean • Put plaster on arm

	<ul style="list-style-type: none"> • I want the right treatments • My brother went to hospital
Know and understand about disability	<ul style="list-style-type: none"> • They need to know about disability • They need more training to get it right first time • Nurses should understand
I don't mind going to hospital if I have looked around the place first	<ul style="list-style-type: none"> • Visit the ward and meet staff before I go • Hospital map • Let me have a look around the place first • I'm happier to go to hospital if I know more • Don't mind going to hospital
Understand what worries, hurts and frightens me	<ul style="list-style-type: none"> • What worries me was when the students were pretending to operate on me • Why do they discharge you early? My friend died. • Understand when it hurts and I am frightened • Talk more about scary health things, like heart attacks. • It's scary when you are asleep and they are doing an operation. You have funny thoughts in your head. • The practice lab can be scary • Heart attacks worry me. • Don't hurt me! • Waiting a long time in hospital makes me more nervous • Some people feel cold in bed in hospital – why can't they have thick blankets? • Waiting time to be seen
What I can do for myself	<ul style="list-style-type: none"> • Undress myself • Know what I CAN do
Hospital is noisy	<ul style="list-style-type: none"> • Hospital is noisy. • Hospitals can be noisy, and hard to sleep in.
Showers, soft beds and modern	<ul style="list-style-type: none"> • Showers • Softer beds and modern

Appendix 2:

Phase 2 of Workshop: Data and analysis

1. Participant groups

Focused on one of the following activities by using the data that emerged from phase 1:

- Developing a purpose of the CoP statement
- Identifying strategic objectives
- Identifying priority actions

2. Participants with learning disabilities

Focused on answering the question:

“What is the most important thing for the Community of Practice to do first?”

Alternative Purpose statements

PURPOSE STATEMENT
Group A Our ultimate purpose is to save lives and reduce health inequalities. We will support all frontline staff and carers in the facilitation of partnership working. Communication, useable policy and procedure, improvement of training and properly funded services are the tools which will be used to improve this.
Group B We believe that the CoP will seek to communicate, raise awareness and campaign to develop knowledge and expertise to ensure those responsible, provide the best health support to people who have learning disabilities.
Group C To reduce health inequalities for people with learning disabilities in Kent and Medway.

Strategic Objectives of CoP

Group A	Group B	Group C
Working together to feel accepted and safe in order to...		

Identify and resolve problems, to educate others to..		To train and educate all practitioners in their roles and responsibilities Mandatory training for GPs and consultants
Influence change and positively at government level to...	Raise awareness in primary care of their requirement to undertake annual health checks for people with learning disabilities groups	
Influence change in culture of ALL organisations at ALL levels to...		To become more person centred
Enable inclusion and partnership, i.e. make it meaningful.	To seek meaningful involvement of people with learning disabilities and all related stakeholder	Partnership working with all stakeholders to improve services and make them fit for purpose
	To produce and publicise a report of recommendations below within 12 months (include missing data) What data is currently available (quantitative or qualitative) regarding the health of local people with learning disabilities?	Identifying metrics for effectiveness
		Save lives to reduce health inequalities and promote better health To develop quicker access to A&E services – dignity and control
		To commission appropriately for all

Priority Actions

Group A	Group B	Group C	THEME
Person with LD has the tools to communicate	Raise awareness for people with learning difficulties through education (university, placements, community experiences) as funding is not always available.		Raising awareness of what people with Learning disabilities can expect
Appropriate information sharing, i.e. hospital passports (sharing awareness and availability) and contact details of community/ hospital LD nurse (who is within the health care system)	Reduce inhibitors (institutional discrimination and ignorance) to promote attitudes that ensure good practice		Share good practice amongst health care staff about the needs of people with Learning disabilities
Managerial support			Managerial support
Clear guidelines in place to support staff to get people with LD to access healthcare that meets their needs and which ensures they are safe (make staff feel safe, to question health staff)	Raise awareness through communication/ via IT resources and community involvement	Education and training for all health professionals on LD, syndromes & various communication methods. Basic training (nurses, GPs) to include LD. Including and listening to people with LD, carers, groups and the literature when setting up programmes	Supporting frontline staff to be aware of the needs of people with learning disabilities (including through influencing education)

Make it work		Once set up to constantly be monitored for effectiveness and possible change if required	Identify ways of monitoring the CoPs effectiveness
		Government support to change legislation All health authorities to work together for standardised practice	Influencing organisations, commissioning and government

2. Feedback from People with Learning Disabilities

What do you think staff in hospital should be able to do to care for you better?

- Explaining what is happening in easy read format. No jargon or complicated words. Use photos.
- People being treated with respect and dignity. Showing people around the hospital.
- Being listened to.
- Talking to other people that know them.
- Asking people what they like to eat and drink.
- Having longer appointments.
- Having information on health problems.