Reasonable Adjustments
Workshop Evaluation Report

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Contents

Contents........................................................................................................................................... 2
  Glossary........................................................................................................................................ 3
Reasonable Adjustments Workshop Evaluation Report Easy to Read Summary........................................... 4
  Report Headlines ....................................................................................................................... 6
Reasonable Adjustments Workshop Evaluation Report.............................................................................. 7
  Introduction ................................................................................................................................ 7
  Background & Methods ............................................................................................................. 9
    Growing Evidence of Local Health Inequalities ........................................................................... 9
    Local Collaboration ................................................................................................................ 10
    Workshop Content & Principles ............................................................................................... 10
  Results and discussion ............................................................................................................. 14
    Results ..................................................................................................................................... 14
    Discussion .............................................................................................................................. 21
  Conclusions and Recommendations .......................................................................................... 25
    Learning Disability Education at EKHUFT / Acute Health Providers ........................................ 25
  References .............................................................................................................................. 27
Appendix 1 Treating patients with a Learning Disability – a ‘what you need to know and how to’ workshop Plan ........................................................................................................................................ 31
Appendix 2 Workshop Powerpoint and session plan ........................................................................... 33
Appendix 3 Mental Capacity Act / Deprivation of Liberty Workshop Report ........................................... 39
Appendix 4 Mental Capacity Act / Deprivation of Liberty Workshop slides ................................................. 40
Appendix 3 Learning Disability Workshop Evaluation – Findings – Cohort 1 ........................................... 46
Appendix 4 Learning Disability Workshop Evaluation – Findings – Cohort 2 ........................................... 48
Appendix 5 KSSLD/COP/Clinical Education Learning Disability Workshop Claims Concerns and Issues Findings ........................................................................................................................................ 50
Appendix 6 K&MLDCOP & Clinical Education Learning Disability Workshop Evaluation feedback analysis.... 56
### Glossary

<table>
<thead>
<tr>
<th>Term</th>
<th>Definition</th>
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</thead>
<tbody>
<tr>
<td>Co-creation</td>
<td>A person centred approach to collaborative to working with all stakeholders including experts by experience to undertake a new piece of work</td>
</tr>
<tr>
<td>Experts by experience</td>
<td>People who have a personal experiences of having or caring from someone who has a particular condition or uses services, in this case having a learning disability.</td>
</tr>
<tr>
<td>Preparedness</td>
<td>A new concept enabling healthcare professionals to make reasonable adjustments for people with learning disabilities</td>
</tr>
<tr>
<td>Cohort</td>
<td>Groups of people, in this case referring to people who attended the first and second set of Workshops.</td>
</tr>
<tr>
<td>Grand Rounds</td>
<td>Hospital Doctors training that occurs on a regular basis</td>
</tr>
<tr>
<td>Care pathway</td>
<td>An outline or road map that guides health and social care professionals as to their role in the persons care.</td>
</tr>
<tr>
<td>Practice development</td>
<td>A process of developing person centred cultures, creatively utilising skills, knowledge, experiences of all involved, employing a suite of tools.</td>
</tr>
</tbody>
</table>
East Kent Hospitals & Kent Surrey Sussex Learning Disability Community of Practice proposed to host Workshops supporting healthcare professionals to make adjustments for people with learning disabilities.

A Kent based team of three ‘Experts by experience’ and three Learning Disability Nurses led the project.

The project used local information and ‘practice development’ tools like Claims Concerns and Issues to engage all participants.

The experts by experience reflected on and learnt about: -
• Being a paid freelance trainer
• Teaching and facilitating an educational programme
• Working in a team
• Their own values and beliefs that motivated them and he responsibility of being the voice for a thousand voices of people with learning disabilities across Kent.
While the workshop was aimed at Doctors, of the 120 healthcare professionals that attended the workshops only 10% had a medical background.

This project found that participants were enthusiastic to take actions to ensure their team were ‘prepared’ to make adjustments for people with learning disabilities.

Learning Disability Education of Doctors and other Healthcare Professionals ought to:-
- Be ‘co-created’ and led by and with local experts
- Use inclusive, experiential and creative educational methods to engage participants
- Enable mainstream professionals to understand how and why ‘preparedness’ is essential to making reasonable adjustments for people with learning disabilities.

Creative use of film and sound recordings might help people better understand the project and its many parts.
Report Headlines

- East Kent Hospitals University NHS Foundation Trust (EKHUFT) and Kent Surrey Sussex Learning Disability Community of Practice (KSSLDCoP) proposed this project to enable non learning disability Hospital based doctors and other Kent based healthcare professionals work more effectively with people with learning disabilities.

- Some outcomes were co-created by EKHUFT and KSSLDCoP, and a team of three experts by experience and three local learning disability nurses across three local health and educational organisations planned and delivered the workshops.

- These workshops encouraged participants to consider the needs of people with learning disabilities, and reflect on the care pathways that do not always facilitate equity of positive and timely outcomes for this ‘patient group’

- Practice Development methods including an exercise called ‘Claims, Concerns and Issues’ were employed to engage participants to ensure that their teams were better ‘prepared’ to assess, treat and handover people with learning disabilities.

- A mixture of national and local data and evidence was utilised to establish the rationale for change locally.

- The inclusion Experts by Experience as facilitators of the workshop and their testimony was universally praised from all participants.

- The reflections of one Expert by Experience is integral to this report, both in the form of the cover painting and written experiences. These reflections provide valuable learning for those interested in person centred project development such as this.
  - Ronnie Treston reflects on his learning as a paid facilitator and educator, working within the team and the responsibility of representing the ‘voices for over 1000 people with learning disabilities in Kent’.

- While the project attracted over 120 participants across the nine workshops, less than 10% were from a medical background.

- Education of Doctors and other healthcare professionals ought to be:-
  - co-created and led by local experts by experience and professionals
  - Utilise creative, experiential and inclusive educational methods and techniques to engage participants.
  - Enable mainstream professionals to understand how and why ‘preparedness’ is vital for reasonable adjustments to be made creating positive timely outcomes.
Reasonable Adjustments Workshop Evaluation Report

Introduction

Following a successful experiential education session with Specialist and Associate Specialist Doctors (SAS) at East Kent Hospitals NHS Foundation Trust (EKHUFT), a successful funding bid lead by EKHUFT Clinical Education was made to Health Education England Kent Surrey Sussex (HEEKSS) to undertake six half day interdisciplinary and interagency workshops focussed on treating people with learning disabilities, applying similar methods.

Two cohorts of co-created workshops were undertaken in Kent and Medway between March 2015 and 2017, amounting to nine workshops, attracting approximately 120 non-learning disability specialist health and social care participants, coming from a variety of backgrounds such as doctors, nurses and allied health professionals from local acute hospitals, primary care, community care and specialist mental health services. Additional to this were three Mental Capacity Act / Deprivation of Liberty workshops were delivered in EKHUFT attracting 88 Hospital staff, that majority of whom with Medical staff. These workshops were facilitated by a local Legal company that delivers healthcare related training.

A meeting of a group of local stakeholders including experts by experience helped identify the aim of the workshops: -

“To engage participants in the delivery of person centred, safe and effective care and support for people with learning disabilities, through experiential and reflective activities and educational opportunities. To enable participants to set their own agenda, examine their own practice pathways of care, identifying potential adjustments that could be made.”

A project team –made up of three learning disability nurses and three experts by experience -honored the aim, utilising locally developed data and tools, national evidence, and experiential educational methods to identify a rationale for participant action.

This report draws upon two main data sources:-

1. Participant data – Background, themed fourth generation evaluation (Guba & Lincoln, 1989) data and workshop evaluation data.
2. Expert by Experience reflections

This report intends to add weight to the well documented evidence that inequalities people with learning disabilities experience are primarily predicated on systems that can only be challenged by collaborative effort and coordinated action.

Based on the above data sources, the workshops methods, content and project team, and the Kent Surrey Sussex Community of Practice (KSSLDCoP) are reviewed in context of current evidence, along with the expectations of the participants.

Participants acknowledged the challenges that people with learning disabilities experience in accessing their services, and identified several activities that they might make reasonable adjustments under the Equality Act 2010 in their workplace to ‘ensure professional preparedness’ for people with learning
disabilities to use their services. Preparedness is considered as the optimal state in which to deliver care adjusted to the needs of the person with learning disabilities.

Participants all valued the co-created element of the workshops and evaluated the experts by experience’s role as essential to their engaging the subject matter. This evaluative data is complimented by Ronnie Treston’s reflections on being integral to the team and the workshop project objectives, being valued as a paid member of the team, and offering the opportunity to use tools and frameworks to order his thoughts, to enhance participants learning and to gain confidence which has resulted in more regular paid employment utilising the facilitation skills acquired during the workshops, but most importantly feeling the responsibility of ‘representing over a thousand voice of people with learning disabilities in Kent’.
Background & Methods

In the context of Kent Surrey Sussex Deanery reducing capacity and accessibility of learning disability education sessions for Foundation Doctors in 2014, a group consisting of a learning disability nurse, a student nurse, and three people with learning disabilities facilitated 45 minute education session for Specialist and Associate Specialist Doctors in the Harvey Hall at Kent and Canterbury Hospital. Fourth Generation Evaluation (Guba & Lincoln, 1989) was employed to establish learning needs and provide some local knowledge, and experiences of people who had used the services. Analysis of this evaluation indicated that this cohort required support in several areas:-

- Recognising people with learning disabilities,
- Communicating effectively,
- Assessing abilities to make choices,
- Managing when a best interests decision was required,
- Working with the patient and significant others, and
- Managing the time required for this.

Growing Evidence of Local Health Inequalities

Within the east Kent there was a growing body of evidence of the inequalities that people learning disabilities experience:-

1. National publications
   a. Mencap (2012) published two cases of people with learning Disabilities who died in East Kent Hospitals – Christian Harrison and Barbara Mushett, whose experiences of hospital care were characterised by – failure to assess pain, poor communication, delays in basic treatment, lack of basic care, inappropriate use of Do Not Attempt Cardiopulmonary Resuscitate (DNACPR) orders and the Mental Capacity Act (2005)
   b. News media published the case of Andrew Waters (Dreaper, 2015) initially in 2011. Andrew, a man with Down's syndrome and dementia had a DNACPR order employed without sufficient assessment of capacity leading to a poor quality form that was communicated poorly. Andrew's case was taken up by human right solicitors, and eventually the case was resolved with a full apology in 2015.
   c. Public Health England (Glover, 2013, Glover & Brodigan, 2014) published annual reports on the uptake of Annual Health Checks for people with learning disabilities, initially by region then by county. This identified that the South East and later Kent and Medway remained at Annual Health Checks being offered to approximately 40% of the population of people with learning disabilities.

2. Local Evidence
   a. Collaborative work with East Kent Beautiful Information helped build a statistical model influenced by Eccles (2013), enabling comparative data to be sought relating people with learning disabilities. This helped identify that people with learning disabilities were significantly more likely to be admitted via non elective pathways (Emergency), and to
experience repeated admissions for the same or similar health conditions (Marsden, 2016). This data provided the basis for a nationally recognised interagency referral pathway (Marsden & Taylor, 2015).

East Kent Clinical Education utilised this data analysis to apply for funding from Health Education England Kent Surrey Sussex to run six half day workshops primarily focussed at medically trained professionals in a multi-agency, multi-disciplinary context.

Following the successful completion of the six half day workshops, a second funding bid was submitted jointly from East Kent Clinical Education and Kent, Surrey Sussex Community of Practice to the Health Education England Kent Surrey Sussex Intellectual Disability Workforce programme (Matuska, 2015).

Local Collaboration
A series of planning meetings were held with local stakeholders, from NHS provider organisations, social care commissioners, Higher Education Institutes and local third sector, charities and communities. These meetings were intended to be inclusive, and as such a wide variability of abilities and knowledge of the subject area had to be account for in the meeting design.

According to Manley et al (Manley, McComack & Wilson, 2008) practice development is a ‘continuous process of developing person-centred cultures, enabled by facilitators who authentically engage with individuals and teams, blending personal qualities and creative imagination with practice skills and practice wisdom. The learning that occurs brings about transformation of individual and team practices.’ This methodology provided a creative underpinning to engage this multidisciplinary, multi agency, mixed ability and experience group, and several aligned methods were utilised to enable all – where ever possible – to advocate for themselves. In particular the PRAXIS framework (Wilson et al, 2008), fourth generation evaluation (Guba & Lincoln, 1989) and other creative methods like picture cards were employed to establish the purpose, reflexivity, approach, context, intention and stakeholders for the Workshops.

The implementation of the above approaches drawing on the local and national evidence of health inequalities and the data collected from SAS Doctors provided a series of principles, values and content for the workshop, along with a group of volunteers and contributors who would help find venues, catering, the workshop outline and content which ultimately became a team of six workshop facilitators, three learning disability nurses, and three experts by experience. The workshop PowerPoint slides can be found in appendix 1.

Workshop Content & Principles
The six strong team workshop utilised the above data including feedback and reflections from previous iterations, the growing evidence of health inequalities experience by people with learning disabilities in Kent, and feedback from local stakeholders to establish five main workshop outcomes:-

- an understanding of the national and local evidence base -including legal frameworks - relating to access to health care and health inequalities
- support participants to reflect upon their care environment, care pathways and care delivery
• a personal perspective on learning disabilities from experts by experience.

• A working understanding of ‘reasonable adjustments’ using the 4C Framework (Marsden & Giles, 2017).

• An opportunity to feedback on the action undertaken post workshop.

These outcomes were consistent across both cohorts of workshops; in the first cohort a conference was arranged to enable workshop participants to share their progress with developments in practice or systems, while the second cohort participant feedback was shared at the 2016 Kent Surrey Sussex Learning Disability Community of Practice Conference.

There was an assumption that those attending these events would have had that foundation and have experience of clinical practice. As such it was believed an experiential learning model (Kolb, 1976) would offer the best results, enabling the adult learners to consider familiar clinical situations in detail and through the use of participative exercises, reflection on clinical practice could take place, with an idea that each participant would take back the reflections to action in practice.

The multi-agency multidisciplinary non learning disability specialist participants also reinforced the necessity for an experiential adult learning approach to enable all participants to exchange ideas, identify limitations and boundaries and consider actions that would improve the situation for individual patients.

With this in mind skilled facilitation (Heron, 1999) was required to enable participants to identify their own gaps in knowledge, or more often engagement in doing things that ought to be done (Schwarz, 2002). This was true of both workshops and of chairing of the day, requiring focus on learners’ experiences through preparation of the environment. Reflexivity is paramount with flexibility to change direction in response to experiences and feelings.

The workshops employed two data collection methods during the workshop:

1. Fourth Generation Evaluation data in the form of Claims, Concerns and Issues (Guba & Lincoln, 1989, FoNS, 2018). Fourth Generation Evaluation is action orientated, and considers collaboration to be dependent on negotiation. According to Koch (2001) this negotiation is with the aim of enabling all

Claims, Concerns and Issues (Guba & Lincoln, 1989)

Claims, Concerns and Issues (CCI) is a versatile, flexible and inclusive group activity for gathering feedback, establishing shared purpose and collaboratively setting agendas.

It is a practical tool based on Guba & Lincoln’s (1989) theory of Fourth Generation Evaluation, acknowledging collaborative activity and shared decision making is based on negotiation.

The CCI Facilitator and the group will establish the theme for consideration, then each member of the group with contribute a:-

**Claim** – a positive statement that someone might declare about the subject.

**Concern** – a worry or negative statement about the subject.

**Issue** – A reasonable question a person might ask about the subject.

This information can be collected in many ways, in the Workshops Post it notes and Flip chart were employed. This added a degree of anonymity, and by gathering together similar to Figure 1, the post it notes can be grouped together in themes.
stakeholders to have a voice about issues that directly impact them. According to Guba & Lincoln (1989) claims, concerns and issues is the method that enables the user to elicit stakeholder opinion in a safe environment, defining the course to be followed. This tool can also be used to facilitate and enable reflection, and to stimulate discussion and debate.

Within the Workshops, this activity would be situated after ground rules and introductions, so designed to encourage participants to connect with their own and others reasons for attending, while enabling creative and reflective questions as to practice challenges. These were facilitated using post it notes and flip chart (See Figure 1), enabling a degree of anonymity and supporting collaborative thematic analysis. This data allowed the facilitating team to acknowledge the particular questions and challenges that participants were bringing into the workshop space, enabling the team to support the participants to examine those issues and create value.

![Figure 1 Example of Themed Claims, Concerns and Issues](image)

2. Evaluation data responding to three main questions, one thing I liked about the workshop, one thing I’d change about the workshop and one thing I’ll do as a result of being at the workshop. The simplicity of this evaluation design and methods – using post it notes and flip chart - was influenced by and linked to the comfort and ease that participants found from engaging in Claims Concerns and Issues. The responses were reviewed after each workshop by the team and themed employing a similar process.
Further to this this evaluation will draw upon a creative and reflective response to the experience of being an expert by experience within the Workshop team.

Lastly, aligned with the second cohort were two workshops on Mental Capacity Act 2005 coordinated by East Kent Clinical Education. A report and slides for these events can be found in Appendix 2 & 3.
Results and discussion

Results

Attendance

Aligned with the report outcomes, Figure 1 outlines numbers and professional backgrounds of participants. This data indicates that while the workshops were intended and prepared for an intended audience of Doctors in Kent along with other mainstream healthcare professionals, only approximately 10% of those that attended were medical professionals, coming from a selection of primary, secondary and tertiary care.

Participant numbers fluctuated during the programme, with two workshops having to be cancelled due to the workshop minimum of 8 participant bookings not having been reached. Variation of bookings did not always correlate with times of the year where the NHS might be considered more stretched, however maintaining bookings required the whole team to be engaged in sharing the flyer, and inviting people from clinical practice.

<table>
<thead>
<tr>
<th>Dates</th>
<th>Professional Groups</th>
<th>Participant numbers</th>
</tr>
</thead>
<tbody>
<tr>
<td>27th March 2015</td>
<td>Pre-Surgical Preparation Sister, Specialty Doctor, Nurse Practitioners, Safeguarding Nurse, Advanced Nurse Practitioner, Trainee Associate Practitioner, Consultant Surgeon, Staff Nurse, Paediatrics, Day Surgery Ward Sister, Staff Nurse, Day Surgery</td>
<td>15</td>
</tr>
<tr>
<td>2nd July 2015</td>
<td>GP, Safeguarding Nurse, Nurse, OT, Specialty Doctor, Physiotherapist, Doctor, A&amp;E, Occupational Therapist</td>
<td>14</td>
</tr>
</tbody>
</table>
### Pre-Workshop perceptions

Figure 2 outlines the secondary thematic analysis of each of the cohort’s data gathered using fourth generation evaluation, Claims, Concerns and Issues (Guba & Lincoln, 1989). This information was gathered at the beginning of each of the workshops and was utilised during the workshop to support and enable participants to engage in their own reasons for attending, to negotiate and link their questions and queries with the planned outcomes and identify similarities with other participants. Based on this, these themes reflect the pre-workshop considerations of the participants. These secondary themes use only the words of participants, and an example of the analysis can be found in appendix 5. These themes reflect the aspirations to provide care that is

<table>
<thead>
<tr>
<th>Date</th>
<th>Participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>30th October 2015</td>
<td>Specialty Doctor, Nurse – Outpatients, HCA, Outpatients, Core Trainee, Clinical Nurse Service Manager, Health Visitor, Practice Teacher, Sexual Health Nurse Advisor</td>
</tr>
<tr>
<td>11th December 2015</td>
<td>Midwives, Specialty Doctor, Department Manager, Clinical Support Facilitators, Consultant Psychiatrist, Sister, Staff Nurse, Day Surgery, Associate Practitioner – DSU, Associate Practitioner, Assistant Psychologist, Occupational Therapist</td>
</tr>
<tr>
<td>14th January 2016</td>
<td>Trainee Associate Practitioner, Healthcare Assistant, Consultant Psychiatrist, Senior ATO, Staff Nurses, Community Psychiatric Nurse, Associate Specialist, Home Dialysis Senior Sister, Criminal Justice Liaison and Diversion Officer, ITU Nurse, HCA, Assistant Psychologist, Senior Occupational Therapist, Community Mental Health Nurses</td>
</tr>
<tr>
<td>12th July 2016</td>
<td></td>
</tr>
<tr>
<td>27th February 2017</td>
<td>Paediatric Nurses, Surgical doctor, Hospital Liaison Psychiatry staff, Audiology, Commissioners, SALT, Physio, OT, Radiology, Midwives, Mental Health specialists, Rehab Children’s consultant, Early Intervention psychosis, A&amp;E staff</td>
</tr>
<tr>
<td>21st March 2017</td>
<td></td>
</tr>
<tr>
<td>2nd May 2017</td>
<td></td>
</tr>
</tbody>
</table>
person centred, safe and effective, acknowledging that this requires carving using skills set, knowledge base, and attributes and attitudes to work across agencies, systems, and with stakeholders, applying evidence and legal frameworks that may not be familiar, or entirely comfortable.

<table>
<thead>
<tr>
<th>Cohort 1</th>
<th>Cohort 2</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tailored and flexible care to the needs of people with learning disabilities and their families</td>
<td>Providing personalised practice promoting health through confidence in knowledge, education and skills</td>
</tr>
<tr>
<td>Working collaboratively with families, carers and teams around the person with learning disabilities.</td>
<td>Utilising systems for clinical timeliness making swift adaptations to avoid harm events</td>
</tr>
<tr>
<td>Arranging adjustments using the resources available.</td>
<td>Unpredictability and adaptations in communication, application of legal frameworks with families</td>
</tr>
<tr>
<td>Choice making, capacity &amp; consent, knowledge and experience</td>
<td>Acting on adjustments to resource provision in equipment care communication &amp; rehab</td>
</tr>
<tr>
<td>Confidence and competence with communication and organising discharge</td>
<td>Working on the interface, in partnership with services and people</td>
</tr>
<tr>
<td>Systemic methods for being prepared to make adjustments for people with learning disabilities</td>
<td>Clarity in transitions and pathways supporting access to care and research</td>
</tr>
<tr>
<td>Education &amp; training of healthcare professionals to overcome stigma</td>
<td>Improving services &amp; having a voice through employing people with learning disabilities and other experts by experience</td>
</tr>
<tr>
<td>Improving services &amp; having a voice through employing people with learning disabilities and other experts by experience</td>
<td>Safety and safeguarding in an increasingly complex world</td>
</tr>
</tbody>
</table>
Post workshop evaluation

This data was collected from participants at the end of each workshop, using post it notes and flip chart to support relative anonymity. The data was themed, with a secondary analysis (see appendix 6), and finally a tertiary analysis of the participants post workshop actions was established for each cohort. Across both cohorts, the evaluation indicated that participants valued the team of facilitators made up of learning disability nurses and experts by experience, they felt better informed of national and local evidence, and there was unanimity as to the positive learning environment of Canterbury Christchurch University.

The second question harnessed participants feedback as to the changes that they would make to the programme, most indicated more time was required for further activities, and where possible with greater specificity to the audience.

The workshops were designed to be action orientated, and the final evaluation question encouraged participants to identify their particular achievable action when they returned to their work place. These themed activities indicated the participants had considered their sphere of practice that of the team around them and how people with learning disabilities might arrive and depart from their practice or service area. The first cohort recognised the value of the ‘preparedness’ in making adjustments for people with learning disabilities, while the second found their experience led them to want to network more widely and link with local learning disability nurses.

Figure 3 A Table combining themed evaluation data from the two cohorts of workshops

<table>
<thead>
<tr>
<th>Cohort 1</th>
<th>Cohort 2</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>One thing I liked</strong></td>
<td><strong>Energetic local experts by experience and facilitators</strong></td>
</tr>
<tr>
<td>• Informative inter-disciplinary education with expert facilitation by and with people with learning disabilities</td>
<td>• Local tools, frameworks and resources and pathways</td>
</tr>
<tr>
<td>• Better informed about people with learning disabilities and MCA</td>
<td></td>
</tr>
<tr>
<td>One thing I’d change</td>
<td>• Length, timing, specificity – practice focussed &amp; pre-course preparation</td>
</tr>
<tr>
<td></td>
<td>• Nothing</td>
</tr>
<tr>
<td>One thing I’ll do as a result of today</td>
<td>• Communicate key messages, collaborate &amp; network</td>
</tr>
<tr>
<td>Tertiary thematic analysis of actions</td>
<td><strong>Reviewing commissioning, pathways, systems &amp; training to ensure professional</strong></td>
</tr>
<tr>
<td></td>
<td><strong>preparedness to make adjustments for people with learning disabilities</strong></td>
</tr>
<tr>
<td></td>
<td><strong>locally and nationally.</strong></td>
</tr>
</tbody>
</table>

**Mental Capacity Act / Deprivation of Liberties Workshop results**

The first workshop was held at the Kent and Canterbury hospital on the 12th December, unfortunately due to service pressures at the hospital that week 13 people were able to attend; however, feedback was excellent on a well delivered presentation.

The following workshop was held at William Harvey Hospital as a Ground Round on the 19th December, 15 people attended this workshop, again due to service pressures, feedback again was good on the presentation and context.

The final workshop was integrated within a Medical Half Day at the QEQM on the 25th January, as this was a Consultant led and already a highly popular event, 60 persons attended with excellent feedback on the workshop.
Expert by Experience’s reflections on being a Workshop Facilitator

Background
We were a team of three people with learning disabilities or parent carers, some people call us experts by experience because we have a lifetime of knowledge of having or living with learning disabilities. We all had experiences of coming to local Hospitals as patients or relatives of others. We have worked as volunteer trainers at EKHFUFT developing a Training Needs Analysis and teaching regularly on the Health Care Assistants education programme, the Nurses Preceptorship conference, and Doctors induction programme, we also undertook an evaluation of My Healthcare Passport and facilitating events with Hospital staff and local people during Learning Disability Week. Every few months we’d review our work and plan; in 2014 we said that we wanted to be paid for our work.

In 2014 we were invited to a meeting about the workshops with other local people, and organisations. We worked together to plan and arrange the workshops outcomes, using national evidence (Mencap, 2007, Valuing people, 2009, PMHO, 2009) and local evaluations (Mencap 2012, PHE AHC, Marsden & Giles, 2017), legislation (MCA 2005, Equality Act 2010). This group decided that this training must include people with learning disabilities as paid consultants, and we wanted those attending to be participants, learning through doing. We continued to work on these plans with EKHUFT staff and through this process it was agreed that the experts by experience involved should be paid for their time.

Our Roles in the Workshops
We worked as a part of a team with Nurses from EKHFUFT, Kent Community Healthcare Trust and Canterbury Christchurch University. Our role was to work beside and was equal in our decision making, we used KISS – Keep It Short and Simple to ensure that our facilitator team and workshop participants were able to stay focused and explain what they meant.

We worked together on the putting together the presentation, including the easy to read information, using My healthcare passport, collecting our personal experiences of hospital care ready to share. These stories were linked to the information in the presentation. The planning meetings were based around all our attendance, not just the nurses this was an opportunity to work with staff as a paid member of the team.

Themes

Being employees
We were given a chance to be paid for planning and delivering the workshops, as a member of EKHFUFT staff. We were asked to complete a self-employment form, we all needed help with this form. This stated that we were responsible for our own taxes and that the amount of money ought to be declared to the Job Centre, otherwise it could affect our benefits. Some of us – with help from support workers -declared our earnings to the Department of Work and Pensions, those that did not were invited for interviews at the Job Centre and as a result were less comfortable accepting payment. Were we to get paid work on top of our benefits in the future we would ensure that the DWP were fully aware of our earnings. We had to send an invoice form for each piece of work on this project, we’d not used invoice forms before, we developed a template that each of us could use.
Working within the team

Working within the team has helped with using powerpoint, and I used mind mapping to organise my thoughts and plan the presentation. I had not used case studies before, this was a good learning experience and helped me understand other people’s skills and needs. I also have a better understand about my rights to make decisions for myself, on reflection I agreed to previous hospital procedures, but didn’t necessarily understand them myself, I trusted my carer to guide through the process, not being aware that I had choice making ability. We developed stable relationships within the facilitator team and based on feedback, we reflected on the presentations together, planned and tried out new ways of achieving the outcomes. There was equality within the team, which showed the participants about how we can work together.

Facilitating

We helped support the participants in their groups and to make sure there is an understanding of the tasks and be ready to bring ideas to the group, if I felt that group ran out of ideas regarding the case.

When working on case studies, we made sure that the participants were able to make notes by making sure that paper and pens are on each table, and keep people to time, taking time to listen and give feedback if needed.

This workshop project was the first paid position for over ten years, this has helped me get back into paid work.

Personal reflections

Being in hospital can be hard for anyone, I have ended up in hospital loads of times mainly with fits this would have been about six to seven times a year. The hospital knew I had a Learning Disability but wasn’t always able to communicate with me, it was as if because of my learning disability, talking to doctor was like talking different language.

I wanted to help Doctors and Hospital staff to get better understanding, because of each person has needs that are taken care of at home but somewhere new like hospital is very scary and with a better understanding of learning disabilities I could have got right treatment faster.

Being a part of the workshop project showed that one the best ways of training is to meet, to hear and work together, it gave doctors a chance to listen and ask questions of us and our stories both good and bad; we had an intention that doctors were able to see things from our point of view, and that we are representing over a thousand voices of people with Learning Disabilities in Kent. The feedback we got showed they did go back to their areas with a better idea of how to deal with our needs.
Discussion

Workshop Model

Attendance
The initial funding stream was made by East Kent Clinical Education to Specialist and Associate Specialist Doctors Fund, with the specific intention of engaging Doctors from EKHUFT in a multi-disciplinary multiagency context. However, no more than 5 attended across the nine workshops. Consideration was given to the various levers to encourage attendance including personal invitation, sharing of the flyer via senior staff, and traditional routes of communication, including Communications newsletters, CPD credits and communication via Clinical Education.

While attendance figures fluctuated, this was not aligned with traditionally challenging seasonal variations in service requirements. However wider distribution of the flyer to community and primary care services, did appear to correlate with greater array of professionals from children’s, mental health and GP services booking places.

The target audience was not surveyed as to why so few took up this opportunity, however it was speculated that a mixture of clinical commitments, being away from the clinical environment, and prioritisation with limited information and time led to the resulting showing. It also could be posited that linked to Knowles model (1980), adults choose to learn about subjects that have an immediate relevance. Medical professionals in mainstream services may only encounter two people with learning disabilities in every hundred patients, as such the subjective prioritisation for subject learning may have been influential in the low numbers of this target group.

Aligned with this the first cohort’s planned outcomes conference, designed for participants to share their adjustments in practice was cancelled, and their work was utilised in the KSSLDcOp conference in 2016. This re-organisation was due to poor engagement from the original cohort. Greater engagement in the practice based activity and presentation of the outcomes could have been gained by ensuring participants understood this requirement on applying for a place on the workshop.

While the Kent Surrey Sussex Deanery’s previous offer of a two-hour education relating to learning disabilities session to all Foundation level Doctors via Hospital Trust’s medical education department had become less accessible and available, it did ensure that the subject matter was placed within a curriculum associated with a programme of learning, which had regular attendance.

This year LeDeR – the national Learning Disability Mortality Review (2018), has reaffirmed a recommendation that all staff should be provided with training involving people with learning disabilities and their families. New and creative opportunities will need to be sought to ensure healthcare and education providers are able to respond effectively engaging hard to reach mainstream professional groups.

Similar to the MCA / DoLS workshops, consideration must be given to integrating this type of education within professional curriculums and service providers regular, well attended CPD sessions, as these may well offer a greater spread of knowledge and learning.
Curriculum design and Teaching Methods
Both cohorts of workshops were underpinned by critical creativity paradigm (Titchen & McCormack, 2006) and Fay’s complex of theories making up critical social theory (Fay, 1987). These perspectives encouraged the curriculum to be action orientated, to facilitated reflection through doing and experiencing. Aligned (Fay, 1987) critical social theory, Bloom’s taxonomy of educational objectives (1956) and more recently Anderson & Krathwohl (2001) adaptations, encourages consideration of the high levels of educational objectives ought to enable learners to analyse, evaluate and ultimately create. The curriculum of the Workshops was designed as an intensive afternoon of experiential exercises, enabling participants to identify actions that they would undertake once they had returned to the workplace. Following this there would be an opportunity to present outcomes of their changes in practice at a follow up event.

Both cohorts were supported initially to reflect on their reasons for opting for this educative opportunity using Claims Concerns and Issues (Guba & Lincoln, 1989), while scenarios, the use of 4C Framework (Marsden & Giles, 2017), and process mapping (Damelio, 2011) of participants care pathways encouraged and enabled participants to identify instances where adjustments could be made swiftly an easily with preparation. Participant’s evaluations indicated that the teaching methods employed in the workshops were worthwhile, identifying more time for experiential, facilitated activities and scenarios was required. However, in practice the three-part curriculum, including the action in the workplace and the follow up event was unsuccessful. While it was understood that many participants did return to workplace and commence making anticipatory adjustments, there was no independent evidence. In this context the teaching methods applied in the classroom environment had significant application in other contexts and educational opportunities, however the curriculum would require significant adaptation, ensuring participants understood the commitment of the workshop, its application in practice and requirement to present outcomes as part of the evaluation.

Teaching Content
According to the evaluation, participants valued the local evidence and local tools and frameworks, which illustrated the ideas and theories. These elements had been the results of collaborative clinical practice guided by Michaels (2008) recommendations that had been utilised by the health care regulator Monitor in the risk assessment framework (2015).

This well evaluated Workshop content was a precursor to Health Education England core skills education framework (2016); based on the workshop outcomes, this would have sat within a Tier 1, Learning Disability Awareness programme, however the pilot iterations of programmes including these outcomes were going to require a larger time outlay. It was unclear as to how this education would be attended to following the completion of the Workshops.

While content for future education programmes will need to be guided by the Core Skills Framework (Health Education England, 2016), the Monitor compliance indicators have been replaced by NHS Improvement’s Single Oversight Framework which have removed any specific references to people with learning disabilities. As such, the resources – clinician’s time – will need to be accounted for in context of a plethora of other education and training requirements, with little or no requirement of strategic influence or Board oversight.

Both General Medical Council (2015) & Nursing and Midwifery Council (2018) are now encouraging the use of creative and experiential teaching methods that support learners to engage in applying the theory in practice,

Workshop Team
As outlined in the Background & Methods, the Workshops were co-created with local people and stakeholders. The core group that operationalised the workshops was made up of three people with learning disabilities, three Learning Disability Nurses, the Clinical Education Lead and Administrator.

One consistent theme throughout the evaluations was acknowledgment of the value added that the experts by experience – people with learning disabilities – bought to the Workshops. Ronnie Treston has referred in his reflection to some of the important experiences and understanding of his role within the workshops:

1. Administrative – completing the forms and creating invoices to be paid for his work, declaring earnings to Department for Work and Pensions.
2. Working within the team – to be valued team member, using mind maps (Buzan & Buzan, 1996) to plan and order thoughts, to contribute confidently, reviewing and evaluating,
3. Leading and facilitating - to support the participants both individually and as a group to develop their understanding of the activities and parameters of the workshop, to support the development of their thoughts and ideas, and to be organised and in time with the rest of the workshop team.
4. Writing and contributing to this evaluation report.

These above elements align somewhat with those of conducting inclusive research consensus statement (Frankena et al, 2018), while also modelling the values and communication techniques that can be employed and enabling participants to engage in positive and direct interactions with peoples with learning disabilities.

Based on this evaluation, it would appear that participants found working with experts by experience in the Workshops powerful enough to almost unanimously comment on the positivity of their involvement. It could therefore be recommended that when planning any educational activities for mainstream professionals, that the involvement of people with learning disabilities to a greater or lesser extent can improve engagement in the subject matter.

Concepts for further consideration

Preparedness
One of the new areas for consideration is the concept of preparedness. While the Equality Act prompts for mainstream health care professionals to make adjustments, and other project and evidence indicate what examples of anticipatory adjustments might look like (Giraud-Saunders, 2009, CSP, 2016), this workshop was unique in enabling this professional group to explore what this might look like in their workplace context.

Making adjustments can be simple and managed instantaneously, however results indicated that participants would prefer time to prepare for patients that might have idiosyncratic communications techniques or behaviours, this could include explicit evidence individual’s requirements included in referral letters, and on
computer systems that allowed them to deliver the best possible service, unhindered by delays. Receiving this information also requires some acknowledgment and use of it, which required sharing of the importance of reasons for changes in practice.

While many participants indicated they would be sharing the information with their teams, several also indicated they would be asking for support with making specific adjustments based on the care pathway through their part of the service. This would require discussions with managers who might be better able to influence the pathway.

Informatics solutions were also discussed and considered to enable professionals to automatically receive pertinent information about the needs of their forthcoming patients. It was acknowledged that informatics employed in this way can play a disruptive part in developing clinical practice (Christiansen, 2009). While NHS England (2018) are developing a nationwide ‘reasonable adjustments’ flag, it is unclear as to when this will be implemented and whether this will provide the necessary flexibility to build alerting mechanisms to ensure staff have the necessary time to prepare for the persons requirements. Several participants indicated that they would be seeking out details of their local informatics solutions including flagging systems in acute hospital, registers in primary care, and links with their local social care services who can verify if someone has a learning disability. It is envisaged that these local developments will complement the national systems, once they become available.

**Local Communities of Practice**

According to Wegner-Trayner (2015) Communities of practice have three concerns that relate to the purpose that the community can agree on and unite behind. Previously evaluations (Marsden & Field, 2016) distinctions in this definition were observed based on the those involved in the Kent Surrey Sussex Learning Disability Community of Practice (KSSLDCoP), not being exclusively practitioners, but integral are people with learning disabilities and family carers. This Workshop project and subsequently this report have been developed employing these values of person centredness and inclusivity.

The KSSLDCoP (2013) shared purpose provided an ideal platform on which the Workshop project could be delivered; from undertaking this project, two operational themes could be elicited based on population:

1. Social learning opportunities for those professionally and personally immersed in the field of learning disabilities. This will require developments of programmes, projects and events that will engage local people with an interest in Learning Disabilities.
2. Opportunities for collaborative activity with no learning disability specialists across mainstream services, which could take the form of education, research or other projects.

Having the local knowledge, skills and experience, the KSSLDCoP is well placed to respond to the developing understanding of national health inequalities experienced by people with learning disabilities, to monitor the regional requirements and respond with project recommendations.
Conclusions and Recommendations

This report – developed for EKHFUFT Clinical Education – has provided a mixed picture as to success, while the ultimate target audience was not reached, concrete evidence of reasonable adjustments cannot be shared, the project has provided a unique and intensive learning disability education session for over 100 professionals in Kent over a two-year period. The values, method and design of the project team and educational outcomes have been observed by all participants as valuable, and the team have been pleased to be invited to undertake shortened versions of the workshop at regional events and been acknowledged in county wide Awards.

However, challenges remain relating to the engagement of Doctors and other mainstream healthcare professionals and effectively capturing the outcomes of an experiential, social learning programme such as this, that attends to practically attends to the education and training needs of mainstream healthcare professionals as reinforced by LeDeR (2018), Mencap (2018) aligned with the Health Education core skills (2016). As such a series of recommendations can be found below attributed to organisations.

Learning Disability Education at EKHFUFT / Acute Health Providers

Doctors

- To include Learning Disability issues in the mandatory core curriculum of doctors training, involving local people with learning disabilities and family carers.
- To include learning disability issues in to the regular programme of monthly Grand Rounds for hospital doctors training
- Network with Medical Schools Council to incorporate Learning Disability in to the relevant teaching programmes.
- Discuss within Root Cause Analyses post Serious Untoward Incidents and Datix discussions
- Develop links with new Kent Medical School
- Learning Disability Specialist Nurses to have more strategic influence with Director of Medical Education and Medical Director to ensure workforce needs are met.
- Develop and evaluate Simulation Scenarios, where possible involving people with learning disabilities, relating to 4C Framework components.
- The development of Medical Learning Disability leads by faculty.
- Further workshops will be integrated within a Consultant led event
- Future education for Doctors will want to consider quantitative and qualitative evaluation as to attendance and engagement in the subject matter.

Other Hospital Staff

- To include Learning Disability education into the Quality Improvement initiatives and education.
- Ensure awareness is sustained through traditional and new media communications, including all Acute Hospital communication routes such as Trust News, Risk Wise, Trust Webpages and social media.
- To ensure is included in Patient Safety Board activity
- Further support required from HEKSS Programme Development Department
- Utilise partnerships with Higher Education Institutes to develop Learning Disability joint appointments respond to the education needs of mainstream professionals across the whole system.
- Alerting system could enable specialist doctor placements in clinical training to get experiences of people in Hospital.

**KSSLDCoP**
- The KSSLDCoP continues to be a place for collaboration, practice development, education and research.
- The KSSLDCoP will want to consider how it a) supports the educational needs of the community Learning Disability Specialists and stakeholders, while also b) reaching out to mainstream healthcare professionals.
- Leadership opportunities for all stakeholders in the KSSLDCoP are now available, it would appear opportune to develop a vehicle to support this locally.
- Other mainstream healthcare professionals such as specialist dentistry and mouth care may wish to contribute to the KSSLDCoP.

**Education Providers and Commissioners**
- Consider utilising accessible formats to share the experiences of team members and showcase facilitated exercises such as Claims, Concerns and Issues.
References


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Appendix 1 Treating patients with a Learning Disability – a ‘what you need to know and how to’ workshop Plan

Outline

- In-depth understanding of Learning Disabilities
  - Service User's personal perspective
- Interactive and Scenario based sessions
- Legal Duties of Healthcare Professionals
- Leadership and Service Improvement opportunities

Aim of workshop
To engage participants in the delivery of person centred, safe and effective care and support for people with learning disabilities, through experiential and reflective activities and educational opportunities. To enable participants to contribute to the agenda, examine their own practice, pathways of care, identifying potential adjustments that could be made.

Learning Outcomes:
Participants will be provided with an opportunity to:

1. Use Claims Concerns and Issues (Guba & Lincoln, 1989) to identify additional learning outcomes for the workshop
2. Explore the definitions and perspectives of ‘learning disabilities’ and the practical impact in services, including personal testimony and films
3. Current evidence base including national and local evidence
4. Explore themes – Communication, Capacity and Consent, collaboration and Coordination
5. Identify work based activities to improve participants service for people with learning disabilities
6. Gather feedback for future workshops

Process

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<th>Time</th>
<th>Learning Outcome</th>
<th>Process</th>
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<th>Resources</th>
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<td>Set up room</td>
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<td>Tables, posters. Powerpoint access &amp; sound</td>
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<td>Lunch and Networking</td>
<td>Activity</td>
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<td>What is and what isn’t a learning disability?</td>
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<td>Why should we be here talking about people with learning disabilities?</td>
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### Workshop Powerpoint and session plan

#### Introduction

*Treating people with Learning Disabilities Workshop*

Cathy Bernal, Ronnie Treston George, Matuska Steven Chapman, Vanessa Cowley, and Daniel Marsden,

#### Housekeeping

- **5:00**
- **FIRE**

#### Ground rules

#### Workshop outline

- What is a learning disability?
- Experts by experience perspectives
- Interactive and Scenario based sessions
- National and local evidence
- Legal Frameworks
- Leadership and Service Improvement opportunities

#### Workshops Background

- HEKSS funded
- 5 Workshops and one end point conference
- Collaborative project
What is a learning disability?

• The Department of Health defines a Learning Disability as including the presence of:
  • A significantly reduced ability to understand new or complex information, or learn new skills (impaired intelligence), with;
  • A reduced ability to cope independently (impaired social functioning);
  • Which started before adulthood, with a lasting effect on development.

Confusing terms

Mental impairment

Used within the UK legal system

Mental Retardation

Most commonly used term across 147 countries sample by WHO in 2007 76%

Learning Difficulties

Used within UK educational system

Intellectual disability

Learning Disability

Mental Handicap

National Evidence Base

Coverage of Health Checks by region 2012/13

Bar chart comparing admissions to EKHUFT services pwld vs general population (Bailey & Marsden, 2013)

Coverage of Health Checks 2013/14 (Glover & Brodigan, 2014)
How people with learning disabilities used EKHUFT services compared to the general population in 2014/15 (Marsden & Bailey, 2014)

Repeated Admissions to EKHUFT services 2012 - 2015 (Bailey & Marsden, 2015)

What is the MCA
- A statutory framework to ……
- empower and protect vulnerable people who may not be able to make their own decisions
- make clear who can take decisions in which situations and how they should go about this
- enable people to plan ahead for a time when they may lose capacity

Assessing lack of capacity
- Single test for assessing capacity to take a particular decision at a particular time
- Decision-specific test
- No one to be labelled ‘incapable’ as a result of a particular diagnosis
- THIS decision at THIS time for THIS individual

Assessing capacity

Assessing capacity is:
- Decision specific, time specific
  - Because capacity can be decision and/or time specific
- Has a 2 stage test:
  1. Does the person have an impairment of the mind or brain?
  2. If so, does that impairment mean the person is unable to make the decision at the time it needs to be made?
Assessing ability to make a decision

A person is unable to make a decision if they cannot:

1. understand relevant information about the decision to be made
2. retain that information in their mind
3. use or weigh that information as part of the decision-making process, or
4. communicate their decision by any means.

Best interests - The decision maker must:

1. involve the person who lacks capacity
2. have regard for past and present wishes, feelings, values, beliefs and especially any written statements
3. consult with and take into account others who are involved in the care of the person, especially any legally appointed person, eg a Lasting Power of Attorney (LPA) or Independent Mental Capacity Advocate (IMCA)
4. not make assumptions based solely on the person’s age, appearance, condition or behaviour
5. demonstrate and document the process of decision-making

Factors to be considered

- General intellectual ability
- Memory
- Attention and concentration
- Reasoning
- Information processing
- Communication (understanding and expression)
- Cultural influences
- Social context

What may trigger an assessment of mental capacity?

- The way a person behaves
- Concerns raised by someone else
- Receiving a diagnosis
- Major change in care provision

What are Reasonable Adjustments?

4C Framework for Making Reasonable Adjustments (Giles & Marsden, 2014)

<table>
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<th>Communication</th>
<th>Choice Making</th>
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<tr>
<td>Collaboration</td>
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Tools for Adjustments

- Easy Health website
- Hospital/Healthcare Passports
- Hospital Communication Book
- Books Beyond Words
- DisDAT pain assessment tool

Reasonable Adjustments: Case studies

- 2 basic case studies to work up
- No right or wrong answers
- Consider the legal and 4C’s Framework

Questions
- What are you first thoughts?
- What questions do you have?
- How could you answer those questions?
- What action would you take?

Care pathway activity

- Areas for consideration:
  - What can you learn from that experience?
  - What are the assumptions care pathways based on?
- Activity
  - Plot the pathway for the individual.
  - Plot the adjustments that could be made.

Your Care Pathways

- Plot how people come to your service
- Include the steps of your service
- Exit point from your service
- Thinking about 4C’s, are there any adjustments that could be made?

Other reference points

- Kent and Medway Learning Disability Community of Practice
  https://kentlivewell.wordpress.com/
- Social Media for Networking
  http://www.wecommunities.org/
- HEKSS Urgent Care Report
  http://www.canterbury.ac.uk/News/newsrelease.asp?newsPk=2367

What’s next?

- What adjustments could you make?
- What are the first actions to having this happen?
- Final Conference?
References

Appendix 3 Mental Capacity Act / Deprivation of Liberty Workshop Report

Three workshops were delivered across East Kent Hospitals, by John Sheath of Brachers Ltd., a local Legal company that delivers healthcare related workshops.

All Trainees, Doctors and Nursing staff were invited to these workshops

The first workshop was held at the Kent and Canterbury hospital on the 12th December, unfortunately due to service pressures at the hospital that week 13 people were able to attend; however, feedback was excellent on a well delivered presentation.

The following workshop was held at William Harvey Hospital as a Ground Round on the 19th December, 15 people attended this workshop, again due to service pressures, feedback again was good on the presentation and context.

The final workshop was integrated within a Medical Half Day at the QEQM on the 25th January, as this was a Consultant led and already a highly popular event, 60 persons attended with excellent feedback on the workshop.

As a result of this, any further workshops will be integrated within a Consultant led event.

Rags Subramaniam
Appendix 4 Mental Capacity Act / Deprivation of Liberty Workshop slides

DEPRIVATION OF LIBERTY (DoL)

John Sheath
Head of Healthcare
JohnSheath@brachers.co.uk

"The literal words of the Supreme Court’s test (in Cheshire West) are perfectly easy to understand. But for the hooligans who have to administer it at first instance the scope and ramifications of the test, are with respect, extremely confusing”

Mostyn J [Re CD 2015]

Deprivation of Liberty - Agenda

1. Legal Background
2. Practice and Policy
3. Hospital Scenarios
4. The Future

DoLS Legal Background

• The Bournewood Gap - 2004
• JE v DE and Surrey CC 2007
• MCA Code and CoP 2009
• Mig and Meg 2010

• P v Cheshire West 2014
• The “acid test” – it is satisfied if:-
  • A person who lacks capacity to consent to their care/treatment arrangements:-
    – Is under continuous supervision and control
    – Is not free to leave

• Children U16 and Young Adults
• NHS Trust v FG 2014
• R (LF) v HM Senior Coroner for Inner South London 2015
• The Law Society Guidelines 2015
**DoLS Practice and Procedure**

- The "Hospital and Care Home Residence: Deprivation of Liberty Procedures (DoLS)" 2009.
- MCA Schedule A1 and 1A
- DoLS can only be authorised by:-
  1. The Court MCA S.16 (2)(a).
  2. The Supervising Body Schedule A1 MCA.
  3. Authorised body in an emergency situation (S48 of the MCA).

---

**DoLS Hospital Scenarios – Law Society Guidance 2015 (1)**

Factors for frontline practitioners:

1. Degree of duration of any physical restraint.
2. The use of sedation.
3. The use of other invasive treatment, such as catheters and/or intravenous drips.
4. Observation and monitoring levels.
5. Refusal to allow family members any access to the patient (not just merely regulating visiting times).

---

**DoLS Hospital Scenarios – Law Society Guidance 2015 (2)**

6. The requirement for a person to remain in a certain area of the department, and measures imposed to enforce this restriction.
7. A requirement that the person does not leave the department pending further tests or transfer.
8. Whether the person would be permitted to leave (such as if relatives wished to take the patient home) regardless of whether the person or their family have expressed such a wish.

---

**A&E Scenario (1)**

P brought into A&E having taken DD of paracetamol.

P is vomiting, confused and very anxious.

P resists attempts by staff to take blood and start N-Acetylcysteine treatment.

P has to be restrained and sedated.

The treatment will take 24 hours to complete.

P tells staff he will leave at earliest opportunity to complete suicide.

P is placed in side room whilst treatment given.

---

**A&E Scenario (2)**

P is forcibly restrained and prevented from leaving during 24 hour period.

P is 19 years, found by parents after night out fully dressed in shower and singing at top of his voice.

P has large bruise and laceration to left side of head.

Parents take P to hospital, unwilling to have skull x-ray and blood tests.

P has elevated blood alcohol level, fracture left temporal region of skull.

P becomes argumentative and intends to take "train to the beach", no obvious explanation.
A&E Scenario (2) Cont.

P assessed as lacking capacity to make decisions about care and treatment.
Plan to sedate and ventilate to transfer to neurosceince unit to have CT.
During wait P is forcibly restrained to prevent assault of staff.
Administered sedative and verbally dissuaded from leaving.

A&E Scenario (3)

P has learning difficulties, found by care worker on floor.
P has fallen and suffered head injury, has no recollection.
P taken by ambulance to A&E and becomes very agitated.
P tells carer she wants to go home.
Junior Doctor explains to carer P requires observation and tests.
P does not have capacity to consent to remain in A&E.
Carer agrees to stay with P; after 4 hours if P sent home without further assessment or treatment being necessary.

Acute Ward (1)

P is 80 year old lady who lives on her own, found by neighbours slumped on floor.
P admitted diagnosis severe community acquired pneumonia.
P responds P antibiotics and wants to go home.
P assessed by physio and OT team as having significant problems with activities of daily living and unsafe to return home.

Acute Ward (1) - Continued

P adamant she will only return home not residential care.
Treating team consider she should stay for further assessment and suitable care home identified.
P will have to remain on the Acute Ward, no immediate prospect of returning home as no support.

Acute Ward (2)

P suffered serious cerebrovascular accident several years ago.
Diagnosed as being in MCS with little chance of recovery.
P vocalises and can track with his right eye but inconsistent in responses.
P unable to carry out any activities for himself, receives CANH via peg tube.
P requires 24 hour nursing care and constant monitoring.
P on long stay ward of neuro-rehab hospital.

Acute Ward (2) - Continued

P’s wife and children visit regularly and express P’s previous wish to be looked after “at home”.
Wife agrees to make arrangements for P to be cared for at home.
Specialists do not agree that will be in P’s best interests.
Further meeting with treating team required to discuss future.
Acute Ward (3)

P brings her brother Q into A&E at 02:00.
Q is 19 years old, mild learning difficulties.
Q involved in a fight, x-ray confirms broken jaw and a number of broken teeth.
Q is referred to maxillofacial surgeon requiring 3 to 4 hour surgery and GA.
Q will need post-op care, not able to eat solids for up to a week and not able to return home for at least 2 days.
Q is admitted to Surgical Ward, surgeon assesses has capacity to make decisions.
Q gives consent to the surgery, Q is able to return home after 2 days.

ICU (1)

A 45 year old man, no significant PMH.
Whilst out jogging P collapses in front of an off duty nurse, basic life support given.
Ambulance found in VF, shocked back into sinus rhythm.
On arrival at A&E GCS, 3/15 PCI demonstrates lesion of circumflex artery which has to be stented.
CT scan normal, admitted to ICU and intubated and ventilated for temperature management.

ICU (1) - Continued

For 24 hours temperature allowed to mobilise. 48 hours still on ventilator as flexion response to pain but cannot vocalise.
ICU team in consultation with family, perform tracheostomy which is successful but neurology has not changed and long term prognosis unclear.
Repeat CT does not show evidence of significant brain injury. Neurologists consider recovery may occur over weeks to months but necessary to stay in hospital environment.
P’s family are unhappy and want him to return home, healthcare professionals disagree.

ICU (2)

P 55 years old on Acute Ward recovering from removal of large meningioma, persistent minor cognitive impairment.
P suffers pulmonary embolism, transferred to ICU for monitoring.
P wants to leave Ward to have cigarette but advised to stay.
P wants to self discharge.
Anticipated by staff he will require sedative medication to ensure his compliance over the next few days.

ICU (3)

P 55 year old man, diagnosed with oesophageal cancer.
P suitable for oesophagectomy and receives adjuvant chemotherapy prior to operation.
P attends pre-operative clinic for advice and information about operation and perioperative management.
P informed will need 2 to 3 days on ICU post-operatively.
P signs consent form for operation which is success.
P post-operatively is sedated and ventilated on ICU according to plan.
Consultant expects P to discharge in a day or two.

DoLS The Future—March 17 (1)

- DoLS overly technical and legalistic not capable of dealing with increased numbers of people, considered to be deprived of liberty.
- New Liberty Protection Safeguards (LPS).
- Power of hospitals and care homes to issue urgent authorisations removed.
- LPS will apply to other settings.
- Distressing and costly Court process to be replaced by administrative process.
- LPS to apply to people aged 16 and over.
- LPS “Responsible Body” will replace the existing supervisory body.
**DoLS The Future—March 17 (2)**

- Strong link between commissioning of care and treatment and authorisation of DoL.
- Remove from Local Authorities burden of authorising of DoLs in hospital settings.
- Responsible Body will be the Hospital Manager or CCG.

---

**DoLS The Future—March 17 (3)**

- **LPS Conditions:**
  1. Person lacks capacity.
  2. Medical Assessment has confirmed unsound mind within meaning of Art 5 (1) (e) ECHR.
  3. Arrangements necessary and proportionate.
  4. Required consultation has taken place.
  5. Authorisation would not conflict with valid decision of a Attorney or Deputy.
  6. LPS will require an independent review stage – approved mental capacity professional.

---

**DoLS The Future—March 17 (4)**

- **LPS Conditions:**
  7. Approved Mental Capacity Professional (AMCP) referral if reasonable to believe the person does not wish to reside or receive care or treatment at a particular place or.
  8. The arrangements are regarded as necessary or proportionate wholly or mainly by reference.

---

**Defence to Civil or Criminal Liability (1)**

- **Defence under S.4 A (a) and S.5 MCA would continue to cover treatment and contact decisions.**
- **Authorisation up to 12 months and reviewed for a second period of up to 12 months.**
- **Authorisation ceases:**
  1. If person has or regains capacity.
  2. Person is no longer of unsound mind.
  3. The arrangements are no longer necessary and proportionate.

---

**Defence to Civil or Criminal Liability (2)**

- There will be rights of legal challenge to the Court of Protection.
- Interim and Emergency DoL abolished but statutory rights to deprive someone of liberty temporarily in urgent or emergency granted situations specifically to enable life sustaining treatment or prevent a serious deterioration in P's condition.

---

**Brachers**

**QUESTION TIME**

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THANK YOU FOR LISTENING

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Appendix 3 Learning Disability Workshop Evaluation – Findings – Cohort 1

### LD Workshops Funding request information

<table>
<thead>
<tr>
<th>Workshop dates</th>
<th>Attendees' roles</th>
<th>No of attendees</th>
</tr>
</thead>
<tbody>
<tr>
<td>27th March 2014</td>
<td>Pre-Surgical Preparation Sister</td>
<td>15</td>
</tr>
<tr>
<td></td>
<td>Specialty Doctors</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Nurse Practitioners</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Safeguarding &amp; LD Nurses</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Advanced Nurse Practitioner</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Trainee Associate Practitioner</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Consultant Surgeon</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Staff Nurse, Paediatrics</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Day Surgery Ward Sister</td>
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<tr>
<td></td>
<td>Staff Nurse, Day Surgery</td>
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<tr>
<td>2nd July 2015</td>
<td>GP</td>
<td>14</td>
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<tr>
<td></td>
<td>Safeguarding &amp; LD Nurse</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Nurse</td>
<td></td>
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<tr>
<td></td>
<td>OT Nurse</td>
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<td></td>
<td>Physiotherapist</td>
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<td>LD Support Workers</td>
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<td>Doctor, A&amp;E</td>
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<td>Occupational Therapist</td>
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<td>30th October 2015</td>
<td>Specialty Doctor</td>
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<td></td>
<td>Nurse, Outpatients</td>
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<td>HCA, Outpatients</td>
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<td>Core Trainee</td>
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<td>Clinical Nurse Service Manager</td>
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<td>LD Lead</td>
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<tr>
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<td>Health Visitor, Practice Teacher</td>
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<td>Sexual Health Nurse Advisor</td>
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<td></td>
<td>Nurse</td>
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<td>11th December 2015</td>
<td>Midwives</td>
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<td>Specialty Doctor</td>
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<td>Department Manager</td>
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<td>Clinical Support Facilitators</td>
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<td>Consultant Psychiatrist</td>
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<td>Sister</td>
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<td></td>
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<td>Associate Practitioner</td>
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<td></td>
<td>Assistant Psychologist</td>
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<tr>
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<td>Occupational Therapist</td>
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<tr>
<td>14th January 2016</td>
<td>Trainee Associate Practitioner</td>
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<tr>
<td></td>
<td>Healthcare Assistant</td>
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<td>Consultant Psychiatrist</td>
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<tr>
<td></td>
<td>Senior ATO</td>
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<tr>
<td></td>
<td>Staff Nurses</td>
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</tr>
<tr>
<td></td>
<td>Community Psychiatric Nurse</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Associate Specialist</td>
<td></td>
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<tr>
<td></td>
<td>Home Dialysis Senior Sister</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Criminal Justice Liaison and Diversion Officer</td>
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</tr>
<tr>
<td></td>
<td>ITU Nurse</td>
<td></td>
</tr>
<tr>
<td></td>
<td>HCA</td>
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<tr>
<td></td>
<td>Assistant Psychologist</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Senior Occupational Therapist</td>
<td></td>
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<tr>
<td></td>
<td>Community Mental Health Nurses</td>
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<td></td>
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</table>

Total 78

NB: There are currently 51 people on the reserved list for future workshops.
## Secondary analysis of Claims Concerns and Issues analysis

<table>
<thead>
<tr>
<th>Tailored and flexible care to the needs of people with learning disabilities and their families</th>
<th>Working collaboratively with families, carers and teams around the person with learning disabilities.</th>
<th>Confidence and competence with communication and organising discharge</th>
</tr>
</thead>
<tbody>
<tr>
<td>Arranging adjustments using the resources available.</td>
<td>Choice making, capacity &amp; consent, knowledge and experience</td>
<td>Systemic methods for being prepared to make adjustments for people with learning disabilities</td>
</tr>
<tr>
<td>Education &amp; training of healthcare professionals to overcome stigma</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

## Post course Evaluation Findings analysis

### Key Evaluation Themes from first four K&MLDCOP & Clinical Education Workshop

<table>
<thead>
<tr>
<th>I liked</th>
<th>Informative inter-disciplinary education with expert facilitation by and with people with learning disabilities</th>
<th>Better informed about people with learning disabilities and MCA</th>
<th>Overall theme of action</th>
</tr>
</thead>
<tbody>
<tr>
<td>I'd change</td>
<td>Length, timing, specificity – practice focussed &amp; pre course preparation</td>
<td>Nothing</td>
<td>Reviewing commissioning, pathways, systems &amp; training to ensure professional preparedness to make adjustments for people with learning disabilities</td>
</tr>
<tr>
<td>I'll do</td>
<td>Communicate key messages, collaborate &amp; network</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

---

Page 47 of 59
Appendix 4 Learning Disability Workshop Evaluation – Findings – Cohort 2

Attendance

Paediatric Nurses
Surgical doctors
Hospital Liaison Psychiatry staff
Audiology
Commissioners
SALT
Physio
OT
Radiology
Midwives
Mental Health specialists
Rehab
Children's consultant
Early Intervention psychosis
A&E staff

12/7/16 – 18, 27/2/17 – 12, 21/3/17 – 6, 2/5/17 – 8 Total : 44

<table>
<thead>
<tr>
<th>Secondary analysis of Claims Concerns and Issues analysis</th>
</tr>
</thead>
<tbody>
<tr>
<td>Providing personalised practice promoting health through confidence in knowledge, education and skills</td>
</tr>
</tbody>
</table>

Page 48 of 59
| Unpredictability and adaptations in communication, application of legal frameworks with families | Acting on adjustments to resource provision in equipment care communication & rehab | Clarity in transitions and pathways supporting access to care and research |

---

**Post course Evaluation Findings analysis**

**Key Evaluation Themes from K&MLDCOP & Clinical Education Workshop – cohort 2**

<table>
<thead>
<tr>
<th>I liked</th>
<th>Energetic local experts by experience and facilitators</th>
<th>Local tools, frameworks and resources and pathways</th>
<th>Overall theme of Evaluation Theme</th>
</tr>
</thead>
<tbody>
<tr>
<td>I’d change</td>
<td>More time for experiential, reflective activities &amp; scenarios</td>
<td></td>
<td>Local inclusive education team employing experiential and reflective activities encouraging participants to develop practice, making time, adjusting attitudes and utilising tools &amp; frameworks for improving outcomes.</td>
</tr>
<tr>
<td>I’ll do</td>
<td>Share knowledge of law, adjustments and locally developed tools</td>
<td>Liaise, Link and learn from others</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Obtain and apply frameworks and tools</td>
<td>Making time, adjusting attitudes, prioritising pathways</td>
<td></td>
</tr>
</tbody>
</table>
### Appendix 5 KSSLDCOP/Clinical Education Learning Disability Workshop Claims Concerns and Issues Findings

<table>
<thead>
<tr>
<th>Dates</th>
<th>7/12/16</th>
<th>27/2/17</th>
<th>21/3/17</th>
<th>2-5-17</th>
</tr>
</thead>
<tbody>
<tr>
<td>Data Source</td>
<td>- Knowledge and education to provide best practice and independence</td>
<td>- Working in partnership with mental health and learning disability services</td>
<td>- Taught by and supporting people with learning disabilities</td>
<td>- Adapting and advocating approaches to the patient and family</td>
</tr>
<tr>
<td></td>
<td>- Provide friendly face to face, personalised, effective same day services</td>
<td>- Promoting health providing appropriate services, getting feedback</td>
<td>- Comfort and confidence in own and others skills</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Service receives alerts enabling swifter adaptations to be made</td>
<td>- Supporting the rights of people to participate</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

- Taught by and supporting people with learning disabilities
- Comfort and confidence in own and others skills
- Adapting and advocating approaches to the patient and family
- Taught by and supporting people with learning disabilities
- Comfort and confidence in own and others skills
- Adapting and advocating approaches to the patient and family
- Taught by and supporting people with learning disabilities
- Comfort and confidence in own and others skills
- Adapting and advocating approaches to the patient and family
<table>
<thead>
<tr>
<th>Concerns</th>
<th>- People being able to voice their understanding</th>
<th>- Assessing for associated health needs</th>
<th>- Knowledge and understanding in approaches</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Complexity of relationships – safeguarding in the virtual and real world</td>
<td>- Awareness, experience and standard of training required</td>
<td>- Patient, supporters and services take the right approach</td>
<td>- Unpredictability and understanding in provision</td>
</tr>
<tr>
<td>- Linking specialists and joint working – not ‘losing’ people</td>
<td>- Timely opportunities for feeding, hearing</td>
<td>- Interface between agencies</td>
<td>- Understanding safety and circumstances in meeting needs</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Harm caused by lack of resource</td>
<td>- Accessing and understanding people with learning disabilities</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Information for serious decision making</td>
<td></td>
</tr>
</tbody>
</table>
| Issues                                                                 | - Clarity as to whether Mental Health or Learning Disability services are more appropriate? Are there care pathways? | - Employment – filling vacancies & improving access for people with | - Applying legal frameworks protecting and consenting without judgement?  
- Building in adaptations to communicate effectively & applying MCA where necessary?  
- Accessibility, streamlining through clinical | - Engaging in accessible communication and rehab  
- Knowing about ld and action on it | - How do we improve services to treat patient with learning disabilities?  
- Knowledge and link services that can support?  
- How to make time and funding for assessments equipment and training? |
<table>
<thead>
<tr>
<th>learning disabilities</th>
<th>and research pathways?</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Establishing when families can contribute to best interests decision making?</td>
<td></td>
</tr>
<tr>
<td>- Being prepared, having the patients ready for appointments and unscheduled care</td>
<td></td>
</tr>
<tr>
<td>- Transitions and signposting to the right services?</td>
<td></td>
</tr>
<tr>
<td>- What Adjustments can</td>
<td></td>
</tr>
</tbody>
</table>
be made to exercise rehab programmes?
- Seamless care and support as individual moves care services

<table>
<thead>
<tr>
<th>Secondary analysis of Claims Concerns and Issues analysis</th>
</tr>
</thead>
<tbody>
<tr>
<td>Providing personalised practice promoting health through confidence in knowledge, education and skills</td>
</tr>
<tr>
<td>Unpredictability and adaptations in communication, application of legal frameworks with families</td>
</tr>
</tbody>
</table>
# Appendix 6 K&MLDCOP & Clinical Education Learning Disability Workshop Evaluation feedback analysis

<table>
<thead>
<tr>
<th>Data Source</th>
<th>27-3-15</th>
<th>2-7-15</th>
<th>30-10-15</th>
<th>11-12-15</th>
<th>14-1-16</th>
</tr>
</thead>
<tbody>
<tr>
<td>Evaluation – One thing I liked</td>
<td>- Inter-disciplinary education</td>
<td>- Listening, discussing &amp; considering a range of viewpoints</td>
<td>- Talking with and hearing from Vanessa and Steven</td>
<td>- Excellent facilitation and expert knowledge</td>
<td>- Thinking and awareness of LD</td>
</tr>
<tr>
<td></td>
<td>- Interaction with people with learning disabilities</td>
<td>- Considering new information like MCA</td>
<td>- Better informed about learning disabilities</td>
<td>- Positive enthusiastic and useful presentation</td>
<td>- Understanding and insights from Steven and Vanessa</td>
</tr>
<tr>
<td></td>
<td>- Informative and Excellent</td>
<td>- Lunch</td>
<td>- Discussing, learning and exploring possible changes</td>
<td>- Enjoyed the whole day</td>
<td>- Informative, interactive sharing solutions</td>
</tr>
<tr>
<td>One thing I’d change</td>
<td>- Making adjustments for participants</td>
<td>- Changes to practice that participants would like to see</td>
<td>- Earlier longer and not at the weekend</td>
<td>- Provide workshop sessions in</td>
<td>- Greater focus on practice, tools &amp; scenarios</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>- Timing of the workshop on</td>
</tr>
</tbody>
</table>
### Content and presentation of Workshops
- Length and specificity of workshop

### The venue conditions
- Precourse preparation & community scenarios
  - Nothing

### workplace & on specific subjects
- Nothing

### flyer & availability of presentation

---

### One thing I’ll do as a result of today
- Sharing and informing colleagues
- Improving systems to make adjustments
- Making adjustments for individual users of the service
- Review commissioning

- Work with and create links with contacts and networks
- Feedback to my teams
- Key Messages taken away
- Creating Pathways through A&E

- Improve and adjust communication in our service
- Using, sharing training teams to use systems to be prepared to make adjustments to appointments use passport.

- Mental Capacity Act training
- Improving communication for people with learning disabilities
- Using social media to improve networking

- Review & improve guidelines and practice
- Practice specific actions to be prepared to make adjustments for people with learning disabilities
- Share learning with team and explore possible improvements
### Key Evaluation Themes from first four K&MLDCOP & Clinical Education Workshop

<table>
<thead>
<tr>
<th>I liked</th>
<th>Informative inter-disciplinary education with expert facilitation by and with people with learning disabilities</th>
<th>Better informed about people with learning disabilities and MCA</th>
<th>Overall theme of Evaluation Theme</th>
</tr>
</thead>
<tbody>
<tr>
<td>I’d change</td>
<td>Length, timing, specificity – practice focussed &amp; pre course preparation</td>
<td>Nothing</td>
<td>Reviewing commissioning, pathways, systems &amp; training to ensure professional preparedness to make adjustments for people with learning disabilities</td>
</tr>
<tr>
<td>I’ll do</td>
<td>Communicate key messages, collaborate &amp; network</td>
<td></td>
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