

The National Review of Learning Disability services 2011/12

Back ground Information

Choice Support leads a consortium of organisations who recruit and employ experts by experience as part of the Acting Together Programme.

Partner organisations in the consortium are Inclusion North, Skills for People, VoiceAbility, Advocacy Alliance and Living Options Devon.

All experts involved in the LDR were employed as experts and involved in inspections prior to the Review.

26 Experts by Experience who have a learning disability and/or mental health needs took part in the 150 inspections as part of National LD review.

All have direct first-hand experience of using services.

Family carer Experts by experience were recruited by The Challenging Behaviour Foundation as part of the acting together programme with the exception of 5 Family carer Experts by experience who were recruited by Choice Support consortium partner Inclusion North. All have caring experience of a relative aged over 16years who has a learning disability and/or mental health needs.

A total of 43 Experts attended the additional training day for the Review

8 Experts were involved in the pilot stage of the LD Review, which included the pilot training and a number of pilot inspections.

The LD Review was a collaboration between Experts, Inspectors, LD Review Lead, CQC's Involvement Lead, Choice Support Lead, and the CBF Lead .

Experts played a valuable and meaningful part in developing an ongoing evaluation process in partnership with CQC, a process that continued throughout the LD review. This process used a variety of methods including feedback forms, phone contact, meetings and peer support.

Before the review began all Experts by Experience attended a basic Induction day which was delivered by the support organisations and CQC involvement team members and compliance inspectors or managers.

The induction day covers the role of CQC, the role of the expert by experience, confidentiality, keeping safe, code of conduct, Equality and Diversity, and the

methodologies used ,using a range of training methods including role play and working through scenarios. .

An additional training day was attended by all experts involved in the LD review which outlined the working together as teams, the focus of the LD review inspections and methodology.

Experts were carefully recruited for the LD review inspections using a detailed matching process lead by the support organisations .

The training also looked at the role of the support organisations in supporting the expert with their role.

Experts were involved in developing the documentation used as part of the LD Review. They developed the prompt questions used for the Inspection and Review of Outcome 4 Care and welfare of people who use services and outcome 7 Safeguarding people who use services from abuse. They played an active part in creating an easy read report template, easy read evidence record sheets and other documents used as part of the inspection packs for all the review inspections. This formed part of the inspection pack that was issued to Experts for use on each inspection. .

After each inspection the expert completed a feedback form about the process, the support they received from the support organisation and from the inspector. This feedback was used to review and shape support networks and methodology used.

As mentioned earlier the Experts involved in the LD review all have experience of using services first hand. A high number have experience of using services similar to the those provided at Winterbourne view.(this may have been many years ago for some experts and for some only for a short stay and the services may have been named differently to the term assessment and treatment unit). As there was a potential for distress to Experts during inspections there was a clear process in place for Experts to inform the inspector straight away of anything they either observed or heard or felt that concerned them.

This was also picked up by the support organisation to make sure the individual expert was supported throughout the process. A confidential 24 hour phone line was available for Experts to use as part of the support network in place.

Support for each Expert was person centred as it varied from expert to expert and depended on each expert's needs and requests.

The following are highlighted points from the on-going feedback from Experts throughout the LD Review

Impact.

- The National review of learning disabilities has been a major piece of work that Experts by Experience have been part of.
- Experts by Experience were upset, shocked and angry about Winterbourne View and the panorama programme. Having Bernadette Hanney open the training days outlining the aims and plans of the review gave clarity to the importance of their role, that they could possibly make a difference and each expert by experience was part of a team working together.
- Experts were able to engage with the process, give their comments and suggestions and as a result of their input see things change throughout the process.
- Experts have been generous and flexible, responding to inspections which at times have been at very short notice.
- They have all evidenced a clear commitment to the review.
- Working alongside inspectors has been very positive.
- Since the review inspections have finished one inspector commented with the quote “ I’ve got my portfolio and am starting to plan inspections and suddenly felt a bit lost without an expert working with me, Im making plans to request an expert”.
- Inspectors regularly shared how valuable having an expert as part of their teams were, and working relationships have been healthy.
- Individual experts have grown in confidence, and gained and developed new skills.
- A very strong impact for Experts has been when they have seen extracts from their reports in the Inspectors final report.
- Experts have said they really welcomed the comments from Inspectors and how much this helped them increase confidence.

The impact on people using the services.

- One inspector sent the following message- “Following the inspection that xxx did with me this week at xxxx one of the patients has requested an address for xxxx as she would like to send her a thank you card. This patient said that xxx inspired her and gave her hope for the future and wanted to pass on her thanks in a card.”
- Experts reported back after each inspection that people using the service were happy to talk to them

The impact of the Ld Review on Experts

- Five experts have overcome their own difficult memories of using a similar service themselves in the past, (these were assessment and treatment units) through recognising their own important roles in the inspections to enable others to have their voices heard through reporting their views.
- This has been an important breakthrough for these individuals as it helped them to re channel their emotions and move forward from feeling a victim to identifying themselves as not only a survivor but playing a role in improving services for others.
- An Expert's gave a presentation to newly recruited inspectors describing how challenging it had been for her to understand that some people needed locked environments for their safety, and what helped her as Expert to balance this with her own view point or values as someone with a learning disability. This was very perceptive and poignant,

Advocacy

- A high number of experts shared that a high number of services they visited provided access to advocacy services . Common concerns were shared about the quality and effectiveness of advocates.
- These included “what has the advocate been doing when the person using the service is having their human rights ignored when they are locked up and they are not detained under the Mental Health Act”,
- “ the woman had been living at the service for 7 years and she only thought she was staying for a short time, she's told the advocate she wants help to move for years and nothings been done”
- “the provider employs their own staff as advocates , that's not right”
- There has been a common question of who monitors and checks advocacy services for their quality, effectiveness and value?
- ‘Advocacy is taking action to help people say what they want, secure their rights, represent their interests and obtain services they need’ (Kings Fund 2008) From the common feedback from experts by experience there has been little evidence of this definition in action though the review of learning disability services inspections.

Compliance

- Experts were worried that findings proved less than half of the services visited were compliant.

- Also a big worry from Experts was finding a high number of services were not person centred.
- The lack of meaningful activities, Experts shared that a common theme was people using services said they were bored.
- Experts shared common concerns of lessons not being learned post incident or safeguarding issue in services.
- The length of time some people were living at a service
- The lack of involvement people using a service had on the service being delivered to them.
- The location of many of the services which were remote and away from any local community presence.
- That people using the services didn't feel they had an option or knew of choices of other types of services available.
- Close family/relatives not being involved when the person receiving a services wanted them to be.
- Experts shared a common area that people using a service hadn't had a review of their care.

Areas that could have made the review better.

- The tight timescale and short notice was a pressure but expert knew this was unavoidable due to external pressures.
- A formal write up of the pilot of the ld review .
- An ending to the LD review work where experts could build on their leadership skills and develop an evaluation day.
- An easy read guide to the commonly used sections of the mental health act.

Final Comment.

- The involvement of Experts in the Learning Disability Review has undoubtedly added a dimension that was missing in previous review methodologies. Their influence and impact extends beyond this review and plays a big part in shaping the future of regulatory inspections. Having people involved that understand what it feels like to receive a service keeps any review process on track and ensures we never lose sight of the fact that service provision is about individuals and should be tailored to each person and their unique needs and be safe from abuse..