

3 Lives: What have we learned, what we need to do

June 2014

Background

Tragically there is a litany of abuse of those who are made vulnerable by their circumstances and all too often families who are so integral to fulfilling lives for their sons and daughters are alienated and excluded by the systems. Our beliefs, attitudes and values affect the way all of us treat other people. People with a learning disability and their families have not always been served well by the health and care systems. This cannot be right at any level, and all too often has had disastrous and tragic consequences for individuals with a learning disability and their families. This has particularly been the case where people have been admitted into mental health and learning disability hospital environments. What should have been short-term assessment and intervention programmes, have become long-stay institutional care with sons, daughters, brothers, sisters and other relatives stranded many miles from their homes and families for disproportionately long periods of time. This approach signifies the breakdown in personalised care where individuals and families are central to the care planning processes we have in place.

The Challenging Behaviour Foundation (CBF) works closely with the Care Quality Commission (CQC) to highlight issues and identify concerns through the inspection programme of services for people with learning disabilities and their families. On the journey back from visiting Lisa¹, one of the three lives shared at the event, colleagues from CQC and CBF discussed learning from getting it wrong for people translating to concrete actions that make a positive difference. We must learn and change to ensure that behaviours and practices are in place to prevent more people from suffering from poor damaging and brutalising services. We all have a responsibility and we can all do something.

In the field of learning disability, there has been great emphasis on sharing good practice in the hope that this will inspire and empower others to replicate that practice. However, while this is important, it is clear that simply describing where things go well is not enough. We have not seen widespread replication of care programmes that work well and have the individual and family heart and centre of the process.

“When people die in a train crash, we don’t just look at why other trains ran efficiently and didn’t crash – we look at the circumstances and events that led up to the crash to ensure we put things in place to prevent another one.” Family carer

We agreed to hold an event where we asked people to share their stories, and to use those experiences to identify actions that could be taken. We wanted senior stakeholders from across the health, care and criminal justice system to be part of the event and make commitments to take the right actions within their sphere of influence. Stories about people’s experiences are a powerful vehicle for helping us to make the emotional connection so often missing between what we do and the reality of the individual lived experience.

On 12 February 2014, CQC hosted an event, chaired by CQC Board member Professor Louis Appleby, where colleagues attended and listened to descriptions of three people’s lives. Everyone present was able to identify actions that they would take, within the context of other initiatives and opportunities, to address the issues the stories

¹ Name changed

graphically illustrated. There was a strong commitment to do so. In addition, there are some national initiatives that the identified actions can feed into. There was a consensus that no new structures or mechanisms should be established, but that wherever possible the links should be made to:

- The Joint Improvement Programme Team sponsored by the Department of Health (DH) and led by NHS England and the Local Government Association.
- The DH team reviewing the Mental Health Act Code of Practice.
- The DH Learning Disability Programme Board chaired by the Minister of State.

We recognise that there is already a significant programme of work underway to transform the current parts of the system that fail to meet individual and family need. Additionally, we agreed that we would support the ongoing programmes of work through these stories, to the commitments set out in the DH publication Transforming care: a national response to Winterbourne View Hospital.

This is a report of that meeting and the proposed resulting actions. These have been thematically grouped, based on the discussions and the recorded feedback.

The 3 Lives

The event focused on the lives of three individuals: Connor, Lisa and Kayleigh.

Connor's story

Connor's mum Sara described her son. He was a lively engaging and active child, with a loving and supportive family and a wide circle of friends. He attended a school for children with learning disabilities, where he was very popular and he enthusiastically participated in a range of activities and sports. However, in his teenage years he developed epilepsy, which he found difficult to accept, and his mental health deteriorated. As he moved into adulthood, his family asked for support, but it was not provided and they reached crisis point. Connor was admitted to an assessment and treatment unit near their family home. At this point his family was excluded – although still at school in the sixth form, Connor was now legally an adult. His family did all they could to ensure that staff understood what Connor was like when he was well and what his needs were, which included his relationship with his family. After 107 days in the unit, Sara received a call while at work to tell her to go to the local hospital where Connor had been taken. When she arrived he was on a life support machine – he had had a seizure whilst in the bath unsupervised and had been found unconscious. The life support machine was switched off. He was 18.

Lisa's story

Lisa's story was described by David (who works for NHS England and had recently reviewed her care), Di (CQC inspector) and Viv (CBF). Lisa was "discovered" by a CBF Expert by Experience member of the CQC review team, as part of the learning disability review (www.cqc.org.uk/content/review-learning-disability-services-1) of her service. During the two-day inspection of the assessment and treatment unit, no one set eyes on Lisa – the CBF Expert by Experience was concerned because she was told that Lisa lived in a locked area at the end of a male ward. She did not come out and no one went in. The CBF raised concerns through the usual channels and was "reassured" that Lisa was "well-known", had an advocate, that there were regular review meetings, and that she was very complex and challenging. CBF insisted on pursuing her case and

discovered that she was kept in a locked area, slept on a beanbag, never went out and staff interacted with her through a small letterbox style “hatch”. For example, her food was passed to her through this hatch, and her hair was brushed through this hatch. She lived like this for nine years detained under the Mental Health Act. There was no therapeutic input – it was containment, and it cost an average of £1,800 per day, over £12,600 per week. No one raised concerns about this arrangement until CBF did. Lisa has now moved to a new service and is doing well, but there is considerable work to do to undo the damage caused by living in solitary confinement for so long.

Kayleigh’s story

Kayleigh was described by her mum Wendy. Kayleigh’s journey through assessment and treatment units started when she hit a member of her staff team while in a residential placement. She was placed in hospital services where she encountered other negative behaviours that she learnt. She spent 10 years in these environments, including moving to Winterbourne View as a step-down service for her. She lived at Winterbourne View for almost three years and when it closed she was moved to a low secure assessment and treatment unit 250 miles away from home. This was intended to be a very short-term placement before bringing her back closer to home, and one that Wendy was always opposed to. However, she spent the next 2.5 years there while Wendy tried to get her out. Kayleigh was detained under the Mental Health Act making discharge a very difficult challenge. Kayleigh was subjected to very restrictive measures that were unnecessary and not in her best interest. Her behaviour deteriorated, which resulted in more restrictions – a self-perpetuating cycle that appeared to have no end. The responsible clinician employed by the private hospital that she was in, opposed her discharge and was keen for her to move to a more restrictive (medium secure) service, run by the company she worked for. It took Wendy, supported by a range of other people and organisations and local commissioners, a huge amount of determined effort to enable Kayleigh to move back to her own house in her home area.

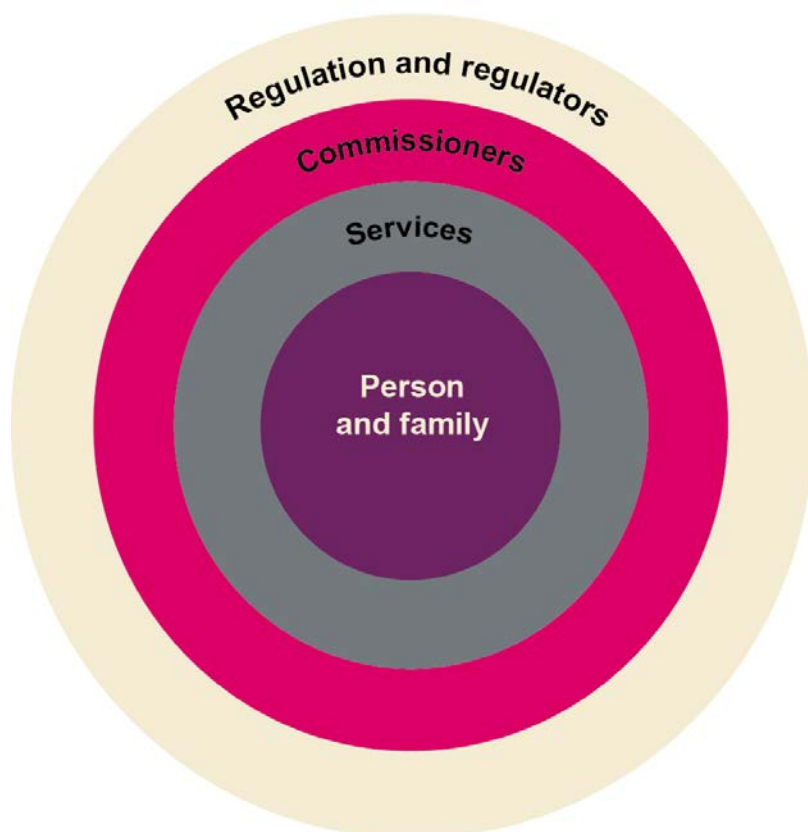
Discussion

After hearing each of these moving stories, attendees discussed the issues and identified where action needed to be taken. There were a number of common themes that related to all three stories. The actions that were identified have been stated and restated previously and in other publications. It is clear that they have not been universally implemented and there is still significant scope for humanising services and protecting individual dignity and rights.

The common themes that emerged were:

- The importance of understanding the person, and listening to them and their family.
- The need for local professional expertise and early intervention close to home.
- The importance of good multidisciplinary support, including transition between child and adult services.
- The closure of services that do not meet people’s needs, and which are at odds with the right models of care.

Legal framework



The main purpose of this event was to seek colleagues' commitments to change for the better for people with learning disabilities and their families. The conversations that took place after each of the stories provided the basis for the actions and who would be accountable for delivering these on behalf of their organisation. These are set out in the table below. Wherever possible, the actions need to build on or feed into existing system structures and programmes. There were no expectations that new programmes structures or accountability arrangements would need to be established. There is not a long list of actions: those identified are challenging to implement but necessary to deliver the system transformation for individuals with learning disability and their families.

Actions

Issue	Action	Who	How will we know?
<p>The health and care system focuses on the system not the individuals and families who are served by the system.</p>	<p>CQC will make this the focus in the inspection programme of services for people with learning disabilities and their families, including using Experts by Experience in the inspections. Inspections will demonstrate a shift to individual outcomes being central.</p> <p>Professional accountabilities need to be emphasised again by professional regulators and royal colleges.</p>	<p>CQC Board will oversee, and hold to account, the CQC executive for the delivery of this programme of work.</p> <p>The Royal College of Psychiatrists faculty of intellectual disability and the Royal College of Nursing are to share these outputs through their networks.</p> <p>CQC and CBF are to formally share this report with the relevant professional regulators and request information about actions that will be taken, and how progress is monitored.</p>	<p>People with learning disabilities and their families will report that CQC ratings reflect their experience of services.</p> <p>By a written commitment from the colleges to uphold the professional standards for care and welfare of patients in learning disability care settings.</p> <p>Responses from regulators.</p>
<p>Individuals are in long-term hospital placements and repeatedly detained under the Mental Health Act (MHA).</p>	<p>The Learning Disability Census and NHS England Quarterly Data Collection to identify who is in the hospital system and the duration of stay. The data must drive commissioner reviews and plans of action for community-based living arrangements.</p>	<p>This is already factored into the DH and LGA sponsored programme of work through the Winterbourne View Joint Improvement Programme (JIP) team.</p> <p>The Royal College of Psychiatrists' training curriculum for psychiatric</p>	<p>Learning disability census data will show reduction in length of stay and length of detention.</p> <p>JIP team reports will report evidence of change.</p>

	<p>CQC MHA Commissioners assessments will be integrated into the model of inspection for Mental Health and Learning Disability Services.</p> <p>The MHA Code of Practice under review to set out parameters of acceptable practice about long-term detention under the MHA.</p>	<p>trainees in learning disability has been revised with Winterbourne issues incorporated.</p> <p>CQC Deputy Chief Inspector for Mental Health and Learning Disability inspections.</p> <p>Department of Health (DH).</p>	<p>Inspection reports.</p> <p>Revised Code of Practice.</p>
<p>There are not enough local multidisciplinary community learning disability services staffed with skilled and able professionals.</p>	<p>Health Education England (HEE) is responsible for workforce development and they must plan for this requirement.</p> <p>The JIP team stocktake data to be used to identify where these services need to be prioritised, including crises support teams.</p> <p>The Royal College of Psychiatrists to lead a review of provision but must include the Association of Directors of Adult Social Services (ADASS).</p>	<p>HEE to be appraised of the data analysis from the JIP team, stocktake by JIP team.</p> <p>The Learning Disability Professional Senate to be asked to plan how to address this, in partnership with HEE and the Royal College of Psychiatrists Faculty, to support planning for learning disability teams at a local level.</p> <p>The Royal College of Psychiatrists Faculty of Intellectual Disability are looking at the evidence base of role and effectiveness of community learning disability services.</p>	<p>HEE has robust plan with measureable outcomes around this specific workforce.</p> <p>HEE workforce plans accurately reflect the development for learning disability staffing across England.</p> <p>Findings to be made available in a report.</p>
<p>Health and care services for people with learning disability and their families are poorly integrated in some parts of England.</p>	<p>NHS England quarterly collections, and the stocktake carried out by the Winterbourne View JIP team, already identify the least well integrated services, and require</p>	<p>This is already factored into the DH and Local Government Association (LGA) sponsored programme of work through the Winterbourne View JIP team</p>	<p>Through JIP progress reports.</p>

	<p>improvement actions and plans from them.</p> <p>Health and local authority commissioners should review all long-term placements, where both duration of stay and costs are excessive.</p>	<p>NHS England, Clinical Commissioning Groups (CCGs), ADASS and the LGA.</p> <p>ADASS to be involved in setting the framework for the reviews/regional monitoring, and for providing support and advice to local authorities where needed.</p> <p>An audit of the work of the care trusts who deliver learning disability support needs to be carried out.</p>	<p>Reported through the JIP, with data being collected by NHS England as part of its routine data collection. From 2015, the data will be collected by Health and Social Care Information Centre (HSCIC) Local Area In-Depth Review Programme, led by the JIP team, will review all these placements and report quarterly.</p> <p>The JIP team should set out the availability of joint services that exist in England.</p>
Whole life planning to support transitional arrangements from children's to adult services is poor across the country.	The system partners need to carry out a proper analysis, supported by epidemiological data, to identify future need and to commission appropriate local community and housing services accordingly.	This is a programme of work that should be sponsored by the DH and LGA as part of their system transformation responsibilities. The proposal should be considered by the JIP team. This work must ensure that commissioners actively engage families and people in the services as part of the programme of work.	Each local authority and CCG area will have a detailed, published plan setting out commissioning patterns and behaviours for whole life learning disability services, based on the assessment of needs. There will be mechanisms identified that these carry the support and endorsement of families and people who use services.
The law is not used effectively and efficiently to ensure that people's rights are upheld.	Convene group of interested and skilled lawyers to clearly set out the legal issues involved in the three stories shared, so that people's legal rights are explained, and legal recourse is available.	The JIP team, CQC and the CBF bring the group of lawyers together to work on a relevant publication that sets out rights and responsibilities.	Clear guidance available and clear pathways to legal support produced by JIP team, CQC and the CBF. The legal group to write guidance for the Crown Prosecution Service in respect of pursuing prosecutions of patients with learning disabilities.
Individuals do not routinely have access to high	CQC and the CBF to write to the Office for Disability Issues and DH to ask how	NHS England data collection on advocacy as part of the JIP team work	More independent advocacy available and used, to ensure good

quality independent advocacy services that meet need. Independent Mental Health Advocate (IMHA) and Independent Mental Capacity Advocate (IMCA) quality assurance	they will address wider strategic independent advocacy issues. DH to be asked for data on IMHA and IMCA availability, quality and use.	to be more specific, and to form part of evidence gathering.	outcomes for individuals. CQC reports to include statement about quality and use of independent advocacy in services.
People end up in services that are available and more secure – rather than in places where they get the support they need.	Need for a national strategy for secure services for learning disabilities. We could then map out present provision and how these pathways work, which would give us an idea of what we need to do things better.	The Royal College of Psychiatrists Faculty of Intellectual Disability to take the lead on this and make a decision about whether they will take this on.	If it is adopted as a programme of work, it will lead to a clear exposition of pathways that meet therapeutic need.
Whole life approach to support and services with seamless transitions,	Child and Adolescent Mental Health Services (CAMHS) must provide assessment and intervention when indicated to individuals with a learning disability.	Royal College of Psychiatrists to establish a small working group to consider care pathways for access to CAMHS and the role of Tier 3 and 4 services JIP team to develop children sub group to plan within the Winterbourne View Joint Improvement Programme.	A national audit of CAMHS services, supported by the JIP team.

Summary and next steps

The quality of provision of care for people with learning disabilities and their families is too variable across England. The use of institutional settings to house individuals for long periods of time away from home communities, and misusing the Mental Health Act legislation must not be allowed to continue. We have compelling evidence from research about what works most effectively for individuals and their families, and we must all continue to push for the implementation of the evidence base.

Community-based care that is person-centred and personalised, and close to family and local contacts, is the model that needs to be available across England. The provision of crisis support teams and positive behaviour programmes make all the difference for individuals and families. Families are very clear that the system should not exclude them as they have much to offer. Indeed, families and individuals needs are often modest and, when met, make a significant difference in keeping people safe, well and in their local communities. Professionals need to recognise this and empathise with the emotional devastation of having your relative sent to institutional care, sometimes hundreds of miles from home.

The effective measure of this will be care closer to home and the relevant number of local assessment and treatment beds, based on rigorous needs assessment. These services, where they do exist locally, will offer assessment and treatment with clear articulation by commissioners of what that means. CQC will inspect these services to make sure that they are safe and offer care to meet local needs only.

The publication of this report by CQC and the CBF will contribute to the plethora of other reports and publications about what needs to be done to deliver safe, effective dignified care for people with learning disabilities and their families. We want the stories shared about these three lives to help all of us working in this system to make what we do more human, more personalised and more meaningful to individuals and families. All of us working in the system must continue to engage with families and through them, and because of them, work tirelessly to make sure that we have local services professionally staffed, responsive, reactive and proactive but always person-centred and personalised.

This report will not in itself make a difference, but our actions can and must. We will invite people to meet again in September 2014 to assess what progress has been made and what more needs to be done.

Attendees

Jane Pritchard; Ian Brown; David Congdon; Beverley Dawkins; Tammy Murray; Ian Brown; Amanda Allard; Karen Turner; Stephen Taylor; Sarah Bernard; Wendy Fiander; Sara Ryan; Jim Blair; Jacqui Shurlock; Ann Webster; Paul Gilluley; L Barrett; Sam Clarke; Bill Love; Bill Mumford; Gavin Harding; Hazel Watson; Marion Janner; Simon Parker; Maggie Graham; Collette Millar; Ben Briggs; Dave Harling; Viv Cooper; Louis Appleby; Sue McMillan; Di Chadwick; Alan Rosenbach; John Devapriam.