

## **CQC LEARNING DISABILITY REVIEW EXPERT BY EXPERIENCE FAMILY CARER PERSPECTIVE**

### **INTRODUCTION**

This report summarises the key feedback from Expert by Experience – Family Carers (experts). A more detailed report will be submitted to the Care Quality Commission (CQC).

It could be argued, that after those who use services, family carers represent the group who are most impacted by poor standards of care.

*“Families are usually the main source of love, care and support for children and adults with learning disabilities. This is especially the case for people with complex needs. Even when people leave home, they do not leave the family. Families continue to offer a lifetime of involvement, support and advocacy.” (Valuing People Now)*

After the Winterbourne View scandal and the announcement of the CQC Learning Disability Review (LDR) the involvement of family carers was debated by the CQC advisory panel. It was acknowledged and agreed, that for family carers to be involved in a meaningful way and have a powerful voice, they needed to not only have the opportunity to provide feedback about their relative's service but should also actively contribute to the inspection process as equal team members.

Experts were recruited through existing partners (Choice Support and the Challenging Behaviour Foundation (CBF)) in the CQC Acting Together Programme. All experts recruited through the CBF had significant caring experience of a relative aged 16 years or over who had learning disabilities (LD) and behaviour described as challenging and/or mental health needs who had either been admitted to, or without the right support could require, specialist intervention from an assessment and treatment unit (A&TU).

CQC produced inspection reports according to their own protocol and in a set format. Following the LDR, the CBF reviewed the process and the experiences of experts, including the themes that emerged and the important issues the LDR raised for them. These are summarised here.

### **THEMES IDENTIFIED**

#### **Service delivery:**

- There was no consistency in the type of service delivered by the units inspected (eg experts identified instances of units delivering a wide range of type and size of service, including services to individuals because nothing else suitable was available).
- Despite the high cost, units lacked the specialism expected from such crucial care, ranging from the quality and expertise of staff through to the therapeutic intervention available.
- Poor environmental factors contributed to low levels of success with rehabilitation. This included size and design of building, standard of accommodation, on site facilities, mix of residents (age, gender, disability, peer group, reason for admission, detained/non-detained).
- Inadequate commissioning, transition planning (admission and discharge), monitoring and inter disciplinary team working resulted in lengthy stays and contributed to readmission. Worse still, some people were inappropriately placed and then “stuck” in the service.

- A functional analysis approach was not routinely employed to identify setting events/triggers to influence positive changes in behaviour described as challenging and minimise the use of physical intervention, seclusion and medication.
- Best interest meetings were not used to support decisions about important issues relating to treatment, health, personal care, and family involvement.

### **Person centred approaches:**

Services lacked a real understanding of and commitment to person centred care which impacted on people's quality of life. Of particular concern was:

- An absence of individualised communication, particularly for those people who were non-verbal or unable to read, eg use of signing, symbols. Receptive skills were over-estimated resulting in the use of communication individuals could not understand.
- No opportunity for people to maintain or develop new skills which would support community living. This inevitably impacted on discharge and future opportunities.
- Enforced participation in meaningless activities in the absence of anything else to do.
- The adoption of a medical model rather than a social model of disability.
- Advocates were not always independent and the standard, availability and input were inconsistent. Having an advocate did not necessarily correspond to better outcomes for the individual.

### **Restrictive practices:**

- Experts had concerns about the use of seclusion. These included prevalence, where seclusion took place, the length of time in seclusion, the way in which people were treated whilst in seclusion and concerns about reporting and recording.
- Excessive restrictions were placed on people's daily lives including their ability to move freely around their accommodation, access to food/drink, participation in preferred activities, cigarette allowance/set smoking times and imposed bedtimes.
- The use of deprivation of liberty safeguards (DoLS) was poorly managed resulting in unnecessary restrictions for others not subject to DoLS.
- There was a lack of clarity about what constituted physical intervention. This influenced what was recorded and reported.

## **FAMILY INVOLVEMENT**

Experts highlighted family involvement as an important area that was commonly not addressed and three main themes were identified:

- **Access:**  
The following examples were encountered and contributed to the breakdown of relationships with relatives, friends and the local community:
  - Rigid visiting hours.
  - Restrictions on telephone contact.
  - Out of authority placements (eg distance, travel time and costs).
  - Location (eg rural setting with poor transport links).
  - Provision for relatives during visits.
  - Contact with relatives used as part of a reward/punishment regime.
  - Visits cancelled due to staff shortages.
- **Information:**
  - Relatives were often unaware of what physical intervention, seclusion, emergency medication (ie PRN) was and whether it was part of their relative's treatment programme.
  - When the above were used relatives were not routinely informed.
  - Relatives were not always clear what represented safeguarding, the process of reporting any concerns or how to make a complaint.

- **Partnership:**
  - Many relatives reported that where admission was as a result of a crisis, they had predicted this and timely intervention could have prevented the need for an expensive, out of authority placement.
  - There was concern by some relatives that if they were identifiable via their feedback, this could have a negative impact on their relationship with the service and/ or the care their relative received.
  - Relatives were not routinely involved in decisions, invited to meetings or asked to contribute to care plans.
  - Whilst some relatives were not completely satisfied with the current placement, if it was better than previous placements, they were content to accept an inferior service and expressed anxiety about discharge plans.

Good practice examples included a monthly newsletter sent out to relatives, family support group on site, the use of technology to promote contact, eg video links, inclusion of relatives/friends/community in planned social events, maintenance of community services, but these were not common.

The LDR was a large, complex and previously unplanned piece of work which had to be carried out within a short timescale. As the robustness of methodology directly impacts on the findings, it is relevant to assess the effectiveness of the process. Therefore, experts provided feedback on the review process itself.

## **METHODOLOGY**

CQCs inclusion of experts within the inspection teams was seen as very positive, but with some important learning points.

### **The positive aspects of the approach were:**

- Relatives interviewed as part of the LDR reported that they felt comfortable talking to another family carer and this made the interview process easier for them.
- All relatives interviewed commented positively about being consulted.
- Carrying out inspections over two days increased capacity.
- Experts welcomed the chance to comment on draft reports before final submission and felt this demonstrated a commitment to involve experts in the whole inspection process.
- Experts mostly felt well supported by lead inspectors.
- Although investigating safeguarding alerts is the responsibility of individual local authorities, any concerns reported during the LDR have been, or are still being, monitored to conclusion by CQC.

### **However, a number of limitations that could impact on the depth of findings were identified and are outlined below:**

- Experts identified that splitting attendance of team members over two days created the following disadvantages:
  - No opportunity to meet and work with all team members.
  - Attendance on day two meant experts missed the impact of arriving unannounced on day one and prevented them observing the service being delivered to people at the outset of the inspection.
  - If relatives interviewed on day two raised new concerns there was limited time available to investigate and triangulate this information.
  - Arriving late morning on day two restricted the time available to make an effective contribution and experts felt that a conclusion about a service had often already been reached.
- Interviewing the relatives of people using services being inspected was the main focus for experts. Most interviews took place via telephone. Experts' views about this process were:
  - Contact details of relatives interviewed were provided by the service being inspected so there was no guarantee of a non biased sample.

- Experts first had to explain the role of the CQC as many relatives interviewed were unfamiliar with them or their role.
  - The standard interview for relatives, developed by CQC, was lengthy and contained irrelevant questions, which frustrated both the interviewer and interviewee.
  - Lack of previous consultation meant that initially relatives were suspicious and needed reassurance that there was no sinister, underlying reason for their involvement, eg cost cutting exercise, proposed changes in placement, safeguarding investigation.
  - There was no debriefing process which meant that relatives interviewed had no way to comment on their experience, withdraw consent or provide additional information.
  - For some relatives the interview ignited emotional memories and there was no support mechanism for this eg where to access further help.
  - Poor support for relatives resulted in experts providing a listening ear which could distract from the focus of the interview.
- The quality of care provided outside office hours (eg early morning/evening) and during weekend and holiday periods was not investigated and this was a serious omission (eg staffing levels, care during shift changes, use of bank staff and element of surprise reduced).
  - Where portfolio inspectors were also lead inspectors this introduced a potential conflict of interest.
  - Experts raised the following issues related to the inspection reports:
    - Lack of clarity about the target audience.
    - Restrictions on the length, what could be included and standard phrasing resulted in bland reports and diluted the reported findings.
    - Authors had to ensure that they were providing sufficient detail without identifying individuals.
    - Where good practice was identified, experts were disappointed that this could not be included in any great detail to encourage other services to model good practice.

## **KEY RECOMMENDATIONS**

### **THEMES IDENTIFIED**

#### **Service delivery, person centred planning, restrictive practices**

- A&TUs to demonstrate at the point of registration, in their service specification, what they provide, who for, how they will assess and treat people and how the service is specialist compared to local, community based provision.
- Front line staff should be highly skilled and qualified, receive advanced training, have a working knowledge of current good practice and receive appropriate support to carry out this specialist role.
- The ability of the service to deliver person centred care should be established by the commissioner prior to admission.
- A clear, standardised pathway for admission and discharge to be implemented across all registered A&TUs and monitored by CQC.
- Clear guidance is needed on what constitutes restrictive practices (including seclusion and physical intervention).
- Services to use positive behaviour support to reduce the use of reactive strategies.
- Access to independent, specialist (eg trained in non-verbal communication) advocates to be a standard requirement.
- A process identified to enable examples of good practice to be shared.

## **Family involvement:**

- Placement costs to include provision to ensure that links with relatives, friends and the local community are maintained (eg travel costs, overnight accommodation for relatives, dual funding to maintain community care package).
- Family carers to be routinely involved, with support, in all CQC inspections, including standard, thematic and mental health commissioner inspections.
- All A&TUs to have an involvement policy, with implementation plan, for relatives, friends and the community.
- A process identified to enable examples of good practice to be shared.

## **METHODOLOGY**

- All team members to attend inspections on both days.
- All inspections to remain unannounced and timings to vary and include early morning/evening/weekend/holiday periods as well as office hours.
- To eliminate a potential conflict of interest, lead inspectors should not inspect services already on their caseload.
- To increase the robustness of the inspection process, periodic peer reviews of services should take place.
- The development of a revised telephone interview format, in consultation with experts, which should include a standard introduction, checklist of topics to be covered (instead of a list of questions), debrief, information about further support and an opportunity for those interviewed to provide feedback on their experience.
- CQC to audit the practice of monitoring safeguarding alerts during all inspection work.
- Clarification of the target audience for inspection reports to ensure they meet their needs.
- In view of the “added value” of the inclusion of experts in the 150 LDR inspections, attention should be given to the Castlebeck service inspections which were carried out under the “old” inspection regime.

## **CONCLUSION**

Every expert who took part did so because they have a child, a brother or sister, an uncle or aunt who had already or could potentially receive care through an assessment and treatment unit. They wanted to take a good look at services for this vulnerable group and make sure that this time their contribution made a difference. They did not want to be part of yet another high profile investigation which led to a well written report which was read, filed and forgotten about until the next scandal.

They used a powerful benchmark “Would I be happy if my relative had to live here?” and in the main the response was “No!” Good provision was an exception rather than the norm. Experts were outraged when they realised that there were still hundreds of people in services which did not meet their needs, leading miserable lives, often for years on end. They were adamant that now they had a true picture they had a moral duty to advocate hard for change.

People who have learning disabilities, behaviour described as challenging and/or mental health needs are entitled to the same life opportunities as others – to be able to live close to family and friends, to be part of their community, to have a choice about where and who they live with, to be provided with capable environments and to be well supported.

There is no need for any further investigations or reports we just need to follow the recommendations already well summarised in Mansell 2007. This responsibility lies with all of us and it is time for action.