

Improving Healthcare Together

Interviews with People with Learning Disabilities (LD)

1) Introduction

Healthwatch Surrey has engaged with the following people with LD:

- Three depth interviews with people with LD (2 female, 1 male, aged between 21 - 53, all White British. One depth interview with the Father of a daughter with LD (63 years old, White British). The interviews were held on Thursday 27th September 2018 in Epsom.
- One group session of 7 people with LD (5 female, 2 male, aged between 20 - 48, 6 White British and 1 mixed ethnic background). Two senior members of staff from The Grange Centre for People with Learning Disabilities also took part in this group session. The group was held on Monday 1st October 2018 in Little Bookham.

2) Priorities / Main Criteria for ‘Good Healthcare’

“We need the best care and the shortest journey”

The people interviewed lived either at home with their parents or in specialist Residential Care with a fair degree of autonomy. Some have local work placements, and most have their own bedrooms within a small sub block with shared living room, dining room and kitchen. Regardless of circumstance, people’s **parents** are usually their central focus in terms of who cares for them (in the broadest sense). Anything which jeopardises that causes uncertainty and fear.

Against this backdrop, some with LD are not *directly* affected by some of the day-to-day logistics of accessing services. They are taken or accompanied there either by a parent, by their community-based carer, or by their care home’s own transport. However, they all adhere to the basic principle that - for acute situations - short journeys are better than long journeys.

“If you had a heart attack, you’d have to drive further. That’s improving the service is it?”

LD are often accompanied by a myriad of other health conditions - so for those making their own way to multiple appointments, consistency is a great advantage.

“I go [to hospital] for four things: bones, ears, epilepsy and diabetes. Always to Epsom”

3) What Needs Improving Most?

For LD respondents, the emphasis is often more on maintaining the status quo than on making improvements. Improvements mean change, and change means uncertainty. However, comments on the relative performance of A&E versus in-hospital services do echo those of carers:

“The first responders were very good, very understanding of the [residential care] environment they were in. But once you’re in hospital it’s not so good; hospital passports get lost or returned and there are misdiagnoses”

Information is also important: *“How do they make people better if they’re feeling poorly?”*
The hospital food comes in for some criticism from one: *“It was crap”*

Staffing shortages are seen by carers for LD as less pertinent than the training which staff receive. Ideally, there would be a specialist LD liaison nurse at every hospital (whether for district or acute situations).

4) The Principle of Integrated and Site-Focussed Acute Services (prefaced by overview of safety / modernity / funding issue)

Many LD participants have multiple health conditions, and they are patients not only at local Surrey and South London hospitals (e.g. St. George’s Tooting and St. Peter’s Chertsey), but also at the major London teaching hospitals such as Guy’s, St. Thomas’ and the National ENT Hospital at UCLH - where they receive more specialist care from audiologists and bone specialists. Respondents understand that any amalgam of *local* acute services would not affect those provided in the capital. That said, there is concern at any potential change:

“There are quite a few ambulances. If they all go to one hospital it might be a bit overcrowded”

“The car park might be a bit crowded. People with LD might find it a bit hard and challenging; they don’t like crowded places. Prefer to be quiet. Also all the nurses would be running around”

Staff shortages were raised as a concern by those with LD - but no link was made between easing this and a one-site approach:

“We’re 40,000 nurses short [nationally] and that won’t get any better if we start banning EU nationals coming here - or even sending them home. If you can’t attract new staff now, how will you if there’s only one site?”

5) Potential Solutions - Acute Services focussed at Epsom, St Helier or Sutton Hospitals

People with LD and those caring for them raise the two familiar concerns about a one-site solution - that it risks danger to patients and severe (if not impossible) disruption for visitors. Epsom is the best-known hospital and generally well-regarded:

“It’s convenient to get to, we get good treatment when we’re there, we get seen (not always on time) and we see the right doctors. We’re also lucky as we have bus passes”

St Helier is not so familiar and few were able to comment on it for good or bad. Sutton is again surrounded by uncertainty - *“I think I’ve heard of it”* - and doubt that it could be a contender as the primary acute site.