healthwatch
Surrey

# People with Learning Disabilities

*Insight into what we've heard*

July 2019

# Contents

## Did you know?

According to the Joint Strategic Needs Assessment for Surrey[1]:

1. Quality of life and length of life for people with learning disabilities (LD) has increased significantly in the last 20 years. However, on average, people with LD have a life expectancy 20 years shorter than the population average. The number of 'healthy years' is also significantly smaller.

2. The proportion of adults with LD in Surrey who work fell by about a third since 2011 and the proportion of adults with LD who live in their own home or with their family is lower than the English average.

3. Around 4,000 adults with LD receive support, including 968 accessing housing support.

4. There are around 21,800 adults with LD in Surrey, 4,600 of whom are 65 or older. This is a high number compared to similar county councils. The number of adults with LD is projected to increase by 10% in Surrey by 2030.

5. Children with special educational needs (SEND) and adults with LD and/or Autism are identified as particularly important population groups in Surrey's Health & Wellbeing Board Strategy. It wants to improve outcomes for this group and provide opportunities for them to achieve their potential.

---

[1] The Joint Strategic Needs Assessment (JSNA): An assessment of the current and future health and social care needs of the local community. The JSNA informs the Joint Health and Wellbeing Strategy which is a strategy for meeting the needs identified in the JSNA. These are needs that could be met by the local authority, Clinical Commissioning Groups or NHS. https://www.surreyi.gov.uk/jsna/

# Executive summary

Over the last year people with learning disabilities (LD) have spoken to Healthwatch Surrey about what's most important to them. Their experience of accessing health services, social care services and other issues that impact health and wellbeing. Parents and Carers also shared their perspective with us.

We heard how people with LD are not a homogenous group and **have different talents, hopes and dreams**. Many people with LD dislike change - and improvements are change and change means uncertainty.

However, we also heard about the **need for flexibility**, as a person's needs change over time. We heard about the importance of employment, and the fact that changes to bus pass rules makes travelling to work more difficult.

We heard that **many people with LD have multiple health conditions**. People told us about the specific challenges they face when visiting hospitals, GPs, sexual health services and dialling 111.

*"I go [to hospital] for four things: bones, ears, epilepsy and diabetes."*

*"If [a person with LD] doesn't understand, can they have an advocate to sign to them? It would be good if staff knew basic signs, like 'toilet.'"*

*"When you ring 111 sometimes the questions are quite difficult. Sometimes people don't understand that you have a LD".*

Parents of children with special educational needs and disabilities (SEND) told us that **there are some people who are 'working wonders'** to support adults with LD and children with SEND to live fulfilling lives.

We also heard that some **parents feel that they are fighting a battle**, and sometimes not listened to by professionals, which can make them feel stressed, belittled and guilty.

*"you think everything is mapped out for you - but it's not"*

We heard that the **transition from 'childhood' to 'adulthood' is particularly difficult.**

# What we did

During our routine evidence gathering activity, over the course of the last year, there were only 14 instances of people talking to us about what it's like to use health and social care services with a learning disability (LD).

We decided to undertake some targeted engagement with this community, whilst raising awareness of Healthwatch Surrey's services.

We spoke to adults with LD and parents of children with SEND in various settings:

- Discussion group with 12 participants at a YMCA group for Young Adults with LD
- Discussion group with 8 members of the Pro-Active Committee at Active Prospects
- Two in-depth interviews with young people (supported by their key workers) who access Young Epilepsy services
- Five in-depth interviews with parents of SEND / LD children who access services at Disability Challengers and the Orpheus Centre.
- Focus groups as part of the Improving Healthcare Together Programme[2]

# What we've heard

People with LD are not a homogenous group, they have different hopes and dreams. One young lady we spoke to has represented GB at the Special Olympics as a cyclist. A young man we spoke to wants to be support worker. Another wants to work in football.

## What matters most to people with LD?

The same as many other people: that we are happy, healthy, safe and fulfilled. The NHS Long Term Plan expresses these priorities as 'Fulfilling Potential, Leading Healthy Lives and Having Good Emotional Wellbeing'.

*There are around 21,800 adults with learning disabilities in Surrey*

Many people with LD dislike change. Improvements are change and change means uncertainty. In our conversations with people with LD, the emphasis was often more on maintaining the status quo than on making improvements.

---

[2] https://www.healthwatchsurrey.co.uk/our-work/reports-and-papers/project-reports/

# Healthcare

## Hospitals

Many people with LD have multiple health conditions.

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

We heard how the Hospital environment can be a difficult place for some.

*“People with learning disabilities might find it a bit hard and challenging; they don’t like crowded places. Prefer to be quiet.”*

*“It might be scary in A&E with drunk people, people with blood on them”.*

People with LD are often taken or accompanied to hospital either by a Carer, by a Care/Support Worker or by their care home’s own transport. Sometimes a person with LD is left to wait alone, and they don’t know whether the reception staff know that they have LD.

We heard that some people with LD would be grateful if more hospital staff were trained in basic Makaton.

*“If [a person with LD] doesn’t understand, can they have an advocate to sign to them? It would be good if staff knew basic signs, like ‘toilet.’”*

We heard that if a person with LD is admitted to hospital, their support worker must leave as ‘they are not funded’.

*“Staff can support in the waiting room but not on the ward. Support [workers] have to leave”.*

We heard that if a hospital has a shortage of beds, the thought of being sent far away to another hospital can be a real cause of anxiety and could lead to increasing feelings of isolation.

## GPs

We heard that self-service check-in at GP surgeries is sometimes difficult, as not everyone remembers their date of birth.

*People with learning disabilities have a life expectancy that is 20 years shorter than the population average*

### 111

We heard that when calling 111, staff do not ask whether you have a learning disability. This means the person with LD must remember to tell the 111 call handler, who can then get appropriate support.

***"When you ring 111 sometimes the questions are quite difficult. Sometimes people don't understand that you have a LD".***

## Specialist services

### Mental health

We heard one complaint about Community Mental Health Recovery Services.

*"**Alfie's**[3] complaint was that the Learning Disability Team at [location] were behaving in a disempowering, threatening and paternalistic way towards him. He was concerned that they were not following the [Mental Capacity Act] Code of Practice, and had carried out a mental capacity assessment without fully explaining its implications to him or his mother. The team have also been coming to his house without appointments, and they have been arranging meetings and communicating about him and not providing any written records."*

### Sexual health

We heard a complaint about changes to sexual health services.

*"**My daughter**, who is learning disabled, had a contraceptive implant fitted on [….]. This was due for removal on […] On researching on her behalf, I discovered that appointment booking is now online. She has no access to the internet. Anyone who was registered with the clinic before the [Clinical Commissioning Group] changed the contract away from [previous provider] to a new provider is no longer registered. I had to re-register my daughter. Dangerous lack of access to old records. The new provider [does not seem able to] access the old records. These were all there, [previous provider] had passed them on. In the case of a learning disability, where someone is unable to recall their history this is dangerous".*

## Social care

### Continuity and flexibility in care provision

We heard about a care provider serving notice on a client, and the cover not being replaced.

---

[3] *Names have been changed and details redacted to protect the anonymity of the individuals that took part*

*“When social services were notified of the cessation of care by […..] they sent out an e-tender. No care company responded. No one told her or her family of the lack of providers willing to make an offer to take on the care.”*

We heard from someone who had lost their advocate and who felt social services had declined. We heard about him being given a new LD support team who might not understand his needs.

*“**Christopher** feels social services within Surrey have significantly declined. He does not have a social worker and when he tries to speak to social services he gets no reply. He has also had problems with his [Care Workers]. Christopher should have 3 hours of care everyday but the care agency he is currently with refuses to send anyone……he previously had an advocate who was enormously helpful to him in finding him suitable accommodation and arranging care for him. This advocate has sadly stopped working and Christopher has been unable to get an advocate since. He also reported that he feels advocacy services have deteriorated as well”.*

*“**Adil** is concerned that whilst he has learning difficulties he also has a physical disability and is worried that this new team will have little or no experience of dealing with physical disability, so may not be able to provide the right support….He feels very frustrated that no one will listen to him. He has tried to complain in the past but nothing has come from it. He doesn't know where to turn or do next”.*

*4,000 adults with learning disabilities receive support*

We also heard from someone who wanted to change the care and support that he accessed to better suit his needs.

*“**Rebecca’s son** suffers from learning difficulties as well as other health issues. He has a care plan and an assigned key worker. He attended […..] but made a decision to stop going in early 2018 and now attends [a service] one day a week […] Surrey County Council […] will not pay for [the service] as they consider it leisure activities not care and development. He has a care support plan. Social Services visited in […] but determined the son’s care plan and financing was ok and there was no further action required. Rebecca wanted to know whether or not they can have the care plan re-assessed as they do not consider it accurately reflects his needs.”*

# Wider determinants of health and wellbeing

## Employment

Some of the people we spoke to have jobs. Often this work was done on a voluntary basis, but in some cases it was paid. We heard that having a volunteer job can be good for anxiety and can provide an opportunity to learn skills which will help in the future with getting a paid job.

*The number of adults with learning disabilities in Surrey who work has fallen by about a third since 2011*

## Benefits

We heard from some people who told us that understanding changes to benefits, when getting either a part-time or full-time paid job, can be very confusing. A lot of people we spoke to know where to go to get help (online, citizens advice, job centre). However, it can make getting a job really complicated.

***“Benefits stops us getting a job... If you work part- time they cut down your benefits”.***

***“We need more information about benefits and work”.***

## Travel

Some of the people we spoke to told us that the new bus pass rules are also a barrier to getting a job, as people with LD cannot now travel before 9:30am for free. Therefore, the potential working day is shortened.

***“The new bus pass rules mean that we can only use it after 9:30am. if my job starts at 9am, I would have to pay for a bus fare rather than getting it for free”.***

## Accommodation

Some of the people we spoke to live in supported living accommodation or residential care. They were happy with where they live.

***“It’s brilliant. It’s on the bus route, it’s easy to get to, It’s close to the town centre, it’s near shops and the bus stop and the doctors. It’s clean and tidy and safe”.***

However, we have also heard from people who were told they were no longer eligible for supported living, and who were sent very large bills to pay for their accommodation which they don't understand.

*The number of adults who live in their own home or with their family is lower than the English average*

We also heard from a lady who was concerned that she would no longer be offered supported independent living, having lived this way for 5 years.

*"**Mark** lives at [….care home] as part of his supported living. He is a vulnerable young adult who suffers from depression and has learning difficulties. When he moved to […] he thought his only expenditure would be the […] charge for utilities. Some time ago he was sent a bill for [large amount], which he did not understand. This was later reduced to [X] and then recently he received a letter informing him that his debt is now [Y] . He does not understand why he owes this amount. Staff at [….] have told him to ignore these letters but his social worker told him he had to pay it. Mark said he did not understand. Other residents at [….] do not pay at all, or much less. He says he has never been given any information, verbally or in writing, about his care and support package."*

*"**Milly** is 23 years of age and has been living in supported independent living for the last 5 years. She loves the accommodation and does not want to move. Her only concern is that she could do with a little more help from a support worker. However, she has just had an assessment by the Transition team from Surrey County Council, who have assessed that she doesn't require supported living anymore. This has naturally put huge amounts of stress and strain on the [client] and her family."*

## Non-specialist accommodation

We also heard from people with LD who don't live in specialist accommodation. They told us that sometimes they feel unsafe and anxious about bullying.

***"Sometimes it's quite frightening, I worry about bullying. Other people/neighbours might pick on you and make you feel uncomfortable".***

## The parents' perspective

### Effective support

We heard how there are many people 'working wonders' to ensure that young lives are fulfilling.

*"The next step is The Grange. It's just lovely and very impressive. They have cooking facilities and a shop there where she can work so that's a long-term objective."*

*"The Grange […] don't just stick them in front of the telly - they [help them] work and study. It's the same with Orpheus. If you want to see a college doing something right, go and see them. They work really hard and have to put on a lot of performances. And it's full of people with different abilities all working together. It prepares them for going into a work environment."*

*"The only true respite I've had in the past few years is St John's in Leatherhead who go on holiday weeks. They're marvelous. The kids absolutely love it. They go to the theatre, the seaside, play games. But she's 19 now so we're not getting that anymore."*

The parents we spoke to were adept at networking via social media and we heard how mainstream schools undertake much of the day-to-day support of those with moderate needs.

### Battles

Parents often spoke in terms of 'fights' and 'battles'. One said "*you just get worn down by it*", and another that "*you have to pick your battles*".

When discussing health and social care services, improvements and specific services were often identified, but just as often was the logistical challenge for some of supporting a young person with SEND / LD to get to school, college or work, on time, day-after-day.

One recurring theme was that schools sometimes chop-and-change over their willingness to accept / keep a young person who has special needs. In some cases, even specialist facilities struggle.

*"you think everything is mapped out for you - but it's not"*

We heard about Carers who felt the system was working against their children, not for them: that they have to fight every step of the way to get a fair deal for their child.

*"Children are assessed against their faults and if you so much as mention a strength you are worried they will be penalised for it."*

*"[Surrey County Council] are so fiercely defensive and protective."*

*"When you are on top form in ideal conditions you have the energy to take people on and make sure your child gets seen and heard, but when your child is ill and not sleeping properly… can cost you a couple of months."*

We heard about very slow or non-existent service provision – cases of families waiting years for assessments, not being offered any help at all, or resorting to private services to make sure their children were able to progress.

*"…there was a huge wait…"*

*"We were told by the paediatrician we'd have plenty of time to get an [Education, Health & Care Plan] but have come to realise this is far from the case."*

*"It comes down to [whether you have] money and that shouldn't determine whether a child is being looked after or not."*

## Early intervention/funding

More than one parent emphasised the folly (as they saw it) of not funding care / treatment for children at an early stage. One view was that early 'investment' maximised the chances of people ultimately being productive members of society.

We heard about lack of signposting and poorly integrated services – parents/Carers who had not been given information on what other services they could or should be accessing to take their child forwards.

*"The GP didn't tell us about the health visitor, I wish she had, we didn't know what she could do."*

*"They assessed him then ran away"*

## Coordination of support

Parents want better co-ordination between the various SEND professionals. Often, they cite very specific examples such as a meeting between case worker and parent, or the need for a school to complete a child's 'Communication Book' daily and not just when something specific happens.

*"**Laura** was referred to the Neurodevelopmental Autistic Spectrum Disorders Clinic… but received a response from this service stating that they were not commissioned to assess individuals with a learning disability. They suggested that [service X] were contacted but did not explain what this service was. Another suggestion was that [service Y] might be approached, which [person] contacted but was told that they could not help either, and they said that it was the GP's responsibility to contact [service X] and that [person] should contact Surrey County Council's Social care Team."*

## Peer support

Many of the parents of children with SEND / LD parents, who may be able offer a wealth of experience and advice to others, told us that they were simply exhausted. Their day-to-day energies often focused on their own child/ren. But online forums and networks of such parents are a valued source of support – practical and emotional – and likewise some of the physical support groups such as those which meet at 'Challengers' in Guildford.

## Parents/Carers, at times, do not feel listened to

We heard of cases where services and professionals failed to take the Carer's knowledge of their child's condition into account, instead relying on snapshot assessments or written reports from third parties. This resulted in inappropriate service offers leading to challenges, unnecessary rework, and wastage.

***"You know your child… so when you tell a professional that your child has repetitive behaviours and they aren't seen in an assessment there needs to be a follow-up."***

***"…in the whole report they picked out 3 lines which said my son was beginning to speak…they failed to realise my son … repeats phrases and says odd words."***

We heard about Carers left feeling stressed, belittled or guilty, either in their interactions with services or by the decisions they had been forced to make as a result of failures in the system.

***"How do they justify putting a family through that [challenging an assessment at tribunal] when we are already under immense stress and pressure."***

***"It makes you feel like you are asking too much of them."***

***"I feel so guilty for [family member paying privately for speech therapy] but my son needs it."***

### Approaching adulthood/transition

We heard how transitions from 'childhood' to 'adulthood' can be particularly difficult. This is certainly true for the parents, but also to varying degrees for the young adults themselves. Those we spoke to with epilepsy have a very low 'comfort zone' threshold, beyond which anxiety takes root very quickly and often dangerously. Therefore, parents/Carers/case workers have a difficult line to walk between involving the young adults in decisions but not prompting harmful physical or emotional reactions.

*"There's got to be a smoother transition than falling off the shelf at 18 years old. Access to medical facilities as a child were very good - I can't complain. I think they did a tremendous job - it's just this transition period."*

*"The problem is that she needs an annual check from the doctor which is right to do so but now she's 18 it means she must go and answer the questions which she can't. Fortunately, I have a brilliant GP who understands us. If she has to run through all the same information again and again she gets bored and begins to play up."*

*"Unfortunately, we lost the local pediatrician from Epsom who knew us and was great, but now we're into Adult Services which is quite frightening for her - having to go into an adult area rather than a child's area. She's still a child mentally."*

## Next steps

This report will be shared with those that took part (and made available in more accessible formats) and with authors of the Joint Strategic Needs Assessment, relevant service providers, commissioning organisations, Surrey County Council, the NHS Learning Disability Liaison Team, GP Federations and Surrey Care Association.

## Acknowledgements

Thank you to those that took part in the discussion groups and in-depth interviews. Our partners provided essential support in connecting us with people. With particular thanks to: Young Epilepsy, Disability Challengers, YMCA East Surrey, The Grange Centre, Little Bookham and Active Prospects.