LLAIS WEST WALES REGION

LEARNING DISABILITIES REPORT

MARCH 2025

LLAIS
Eich llais mewn iechyd a gofal cymdeithasol | Your voice in health and social care

Accessible formats

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About Llais

We believe in a healthier Wales where people get the health and social care services they need in a way that works best for them.

We are here to understand your views and experiences of health and social care, and to make sure your feedback is used by decision-makers to shape your services.

We seek out both good and bad stories so we understand what works well and how services may need to get better. And we look to particularly talk to those whose voices are not often heard.

We also talk to people about their views and experiences by holding events in your local communities or visiting you wherever you're receiving your health or social care service.

We also work with community and interested groups and in line with national initiatives to gather people's views.

And when things go wrong we support you to make complaints.

There are 7 Llais Regions in Wales.

Each one represents the "patient and public" voice in different parts of Wales.

Background

We know that people in our communities across West Wales have different kinds of skills, abilities and needs. Some people need more help and support to live well because they have learning disabilities. They may use health services more often and need support from social care services so they can have full, independent lives and stay safe.

When people with learning disabilities use health and social care services, their experiences may be different from other people who don't have learning disabilities.

Llais hears from a wide range of people across Wales about health and social care. Sometimes we hear good stories where people feel that have been really helped and supported. We also hear negative stories, where things have gone wrong, and people feel let down. When people give us this information, we can meet with health boards and local authorities to share with them what is happening, so that together we can try to make things better for everyone.

We know that we don't often hear from people with learning disabilities about their views and experiences of health and social care. This means that we need to make more of an effort to find out their views and experiences. Instead of waiting for people to contact Llais to share their views, we need to meet with people with learning disabilities, their carers, friends, families and others, to see what we can find out and what they want to share with us.

We planned this work in the autumn of 2024. We told some people about our plans and found that people living in Carmarthenshire, Ceredigion and Pembrokeshire were keen to tell us about their lived experience. In December 2024, to help us further with this piece of work, we used an easy read survey to help people share their views with us.

We didn't know what we would hear about in our survey or how many people would respond to us or if people were tired of filling in surveys.

We didn't know if we would hear mostly good things or difficult experiences, and we were open minded about what we would be told.

People with learning disabilities, their families and carers know they will need some health or social care help for the whole of their lives. This is why it is important that these services meet their needs and work well.

We heard that some people may be nervous about giving negative feedback about the services they receive. So we were keen to make sure that people could tell us their experiences anonymously in whatever way suited them best.

Having to rely on services for a long time, possibly for the whole of your life can mean that it is difficult to complain when things aren't right.

What we did

First, we talked to people with experience of learning disabilities to see what we needed to think about when planning this work. We linked in with Pembrokeshire People's First, Mencap, Learning Disabilities Wales and some parents/carers of adults with learning disabilities.

They were supportive of the work that we planned to do. They felt that often people with learning disabilities were disregarded or their views were not sought or heard.

We had to make sure people could contact us in lots of ways. We heard that some people might want to meet with us in person. Others would want to speak to us by telephone or online chats. Others might want to give us stories by email.

We really wanted to hear directly from people with learning disabilities. To help us with this we prepared survey forms in Easy Read as well as documents in English and Welsh. We asked people to share the forms and documents for us.

What we asked

On our survey form people could answer some or all of the questions we asked. We know people might have a strong view about one subject and have a lot to say but they might not want to share information about everything that we asked.

We asked if people had health conditions as well as a learning disability because it can make day to day life more complicated if they need lots of different health and care services. For example, someone with a learning disability who is a wheelchair user might find it more difficult to use public transport to get to clinics and hospitals.

We asked people where they lived and who they lived with. We know that people living with family members might get lots of unpaid help from parents, partners, siblings or other people. Other people with learning disabilities who live independently may need to pay for support. We also know that people who live in group homes can have some support but also some independence and privacy.

People with learning disabilities might work, study, volunteer or provide care for others and so we asked people how they spent their time. A few people might be very limited in what they could do and would possibly be very dependent on other people for company and activities.

We asked people to tell us about how they used health services. We wanted people to tell us about what was important to them. As part of this we asked people to consider good things, bad things and changes that were needed.

We also asked people to tell us about their experiences when they used social care services. Not everyone uses social care services, and some people might not have anything to tell us. Other people might use several different care services to help them. They might have a carer to give them personal care, to take them shopping, or help them get to work or college. Others might sometimes go to a day centre for respite care or support with activities in general.

In our survey, people could give us their contact details if they wanted to. This might help us contact them again to give us more information and we could send them the findings of our work.

Finally, we asked people to tell us about their age, gender, ethnicity etc. People could answer all, some or none of these questions. We ask for this information to help us make sure that we are hearing from everyone in our communities in West Wales. When we look at this information, we can sometimes see that there may be groups of people that we never hear from. We can then try to do something to make it easier for them to link in with us in the future.

What we heard

We had over 60 responses to our survey. We also had really good conversations with people about the work we were doing. Almost all of the people who responded to our survey came from the three counties in West Wales, with most coming from Pembrokeshire.

We mostly heard from people with learning disabilities themselves. We know some had help to fill in our survey. We also spoke to people by telephone, email and in person.

About a quarter of people said that they had a physical health problem as well as a learning disability. About half the people who completed the survey told us that they had autism or Asperger's syndrome. Several people said they had mental health problems, Down's syndrome or epilepsy. There were also individuals who said they had cerebral palsy, ADHD, dementia and other physical conditions.

People who filled out survey lived in lots of different settings with just under half living in rented or owned accommodation with their family. Most lived in supported accommodation or care homes. Just under half of the people we contacted were living with other people who were not part of their family. A few people lived on their own.

Most people felt that they were getting the support they needed to live in their homes. Some people felt that the support they had wasn't enough and a few weren't sure.

Some people told us how they spent their time every day and the activities they took part in. Most people who answered this question were either involved in voluntary work, looking after their family or in school/college only 2 people told us they were in paid work. A number of people chose not to answer this question.

Having a baby or child with learning disabilities

Some people shared with us their lifetime journey of living with a family member with a learning disability. These were very moving stories about the challenges they had faced over many years.

Although some of these experiences were from many years ago, people could clearly remember how they felt and we felt it was important to shared parts of their stories. People told us that the difficulties they faced often started when their child was very young but continued throughout their childhood and into adulthood.

During pregnancy, most people didn't know that they would have a baby with a learning disability. They expected to have a healthy baby. Sometimes parents will know before their baby is born, that their child will have a learning disability because there are tests in pregnancy for conditions such as Down's syndrome. Other parents may have tests in pregnancy that find an abnormality which may indicate that the baby will probably have some disabilities. But usually, parents expect to have a healthy baby with no problems and learning disabilities are not always discovered when a baby is born or even in the first few years.

"He cried and cried and cried constantly. Even my mother was surprised at how much he cried. This was really draining and although the doctors diagnosed him with colic and reflux, nothing much they gave us stopped him crying."

For first time parents, dealing with difficulties such as constant crying or feeding problems, the early baby stage can be a challenging time. They may be having very little sleep and feel exhausted. They may be dealing with baby care issues and may not always know what is or isn't normal.

As the babies grew into toddlers, we heard that often, unusual behaviours might be noticed by family members with more experience of babies or sometimes by health care professionals. But these different behaviours wouldn't always be linked with a learning disability or developmental problem for a long time.

Parents told us they worried that their baby was different to others of the same age but didn't know who to talk to about this. Parents were told not to compare children with each other because they will develop at their own pace. But, having worries about this situation can make people feel lonely and isolated. It isn't easy to chat with other parents when you are worried that your child is different.

Health visitors are there to support families and particularly first-time parents but relationships with professionals didn't always work well and weren't as supportive as they could have been. Parents felt that they needed help but this wasn't always easy to get.

We heard that it is only when little children failed to meet their developmental milestones that parents started being listened to and taken seriously. Until then, parents often felt as if they were considered to be bad parents who couldn't cope. This meant that sometimes parents felt that they were being seen as the problem.

"...no one seemed to be offering any help. At one point it felt as if the Speech and Language Therapist was blaming us because our child was slow to talk. It was suggested that we weren't engaging with him properly or spending enough time with him. They told us to read to him more and play with him more."

We heard of parents who felt pressurised to attend parenting classes even though they didn't think this was the right answer. We heard that if they didn't agree to attend classes, this could make relationships with health visitors and other professionals even more strained because they were seen as rejecting professional advice.

Families told us that if they lived in a poorer area and didn't have professional jobs, they sometimes felt that health and care professionals were too quick to say that they were not coping.

We also heard that when parents have a child who has some developmental delays and different behaviours, it could be difficult to find appropriate childcare.

"The childminder very quickly said that she couldn't cope with him as he wasn't like other children."

"After half a day in nursery, we were told it wasn't working out."

Lack of childcare provision meant that it wasn't always be possible for both parents to work, particularly if they also had limited family support such as grandparents or aunts and uncles. There could be an unexpected impact on family finances and plans for early parenthood might have to change quickly. A parent may have to stay at home, apply for benefits or make different working arrangements such as becoming a part time worker or self-employed.

Parents often felt isolated and would research to find out more about their child's problems to see there was anyone else in a similar situation. Social media could help, but parents would still feel frustrated at the lack of help available. We heard of one family who travelled to America to try to find ways of helping their child, sometimes having to set up their own support networks.

We also heard that parents were often not told about a diagnosis of 'Learning Disability' and that it was a term that wasn't always used with them.

One mother told us:

"It wasn't mentioned in his medical records until he was about 7 or 8. All of a sudden the term just appeared and we were quite shocked because no one had ever sat us down to explain it. After that, it was a term or a label that appeared on almost everything."

Things were not always negative. We heard how some families had been well supported by professionals who were kind, caring and really empathetic. Meeting people like this could really make a huge difference to parents, extended families and children with learning disabilities.

School and education

Once children with learning disabilities reached school age, it still wasn't easy, it wasn't simply a matter of registering your child at the local school. If a child with a learning disability is able to attend a mainstream school, parents might have to deal with additional meetings, discuss individual adaptations or provide initial classroom support.

Some parents told us they felt relieved that for the first time, their child wasn't seen as a problem but simply a child with different needs and that the education system would work around them. They enjoyed the fact that their child could go somewhere regularly and meet other children.

Sometimes, children couldn't go to the local school and specialist education was needed. This meant that the child had to go to a special school that could support children with additional needs. This might involve travel, specialist transport and the child might not have school friends living close to home.

Even when children had to go to a special school, some parents, for the first time, felt less alone because they could get involved with other parents and children in the same position. They met with staff who were welcoming and who really had a good understanding of the difficulties they had faced. We had some positive comments about school nurses in special schools and how they could be very supportive.

Nevertheless, it can be difficult when a child has to be educated away from their home area or in a different school to other children in the family. Parents may be forced to choose between their children's school events etc and feel that they are struggling to be fair to all of their children. We also heard from parents who felt that they grieved for the traditional school experience that they'd when they were young and which their child couldn't have.

We also heard that parents may have to consider residential schools or accommodation as their child gets older so that their education and care needs could be met. Families could find it difficult when their child was regularly away in the week and came home at weekends and holidays because new routines had to be adjusted to.

Often children gained significantly in confidence and independent living skills when they were living away. They made new friends and developed as individuals. But we also heard that people still worried about their long-term future:

"I am 14 and worry about getting a job. The school have lots of different experience days, but I worry about my chances beyond school and college learning of the experience of others."

Support to go places

From our work we also heard that families of people with learning disabilities often feel that they are left to get on with lots of things by themselves with little help or support. Day to day events such as hospital visits, opticians' appointments, supermarket shopping etc can be demanding. They are often time consuming and tiring, taking a lot more planning than might be needed for people without learning disabilities.

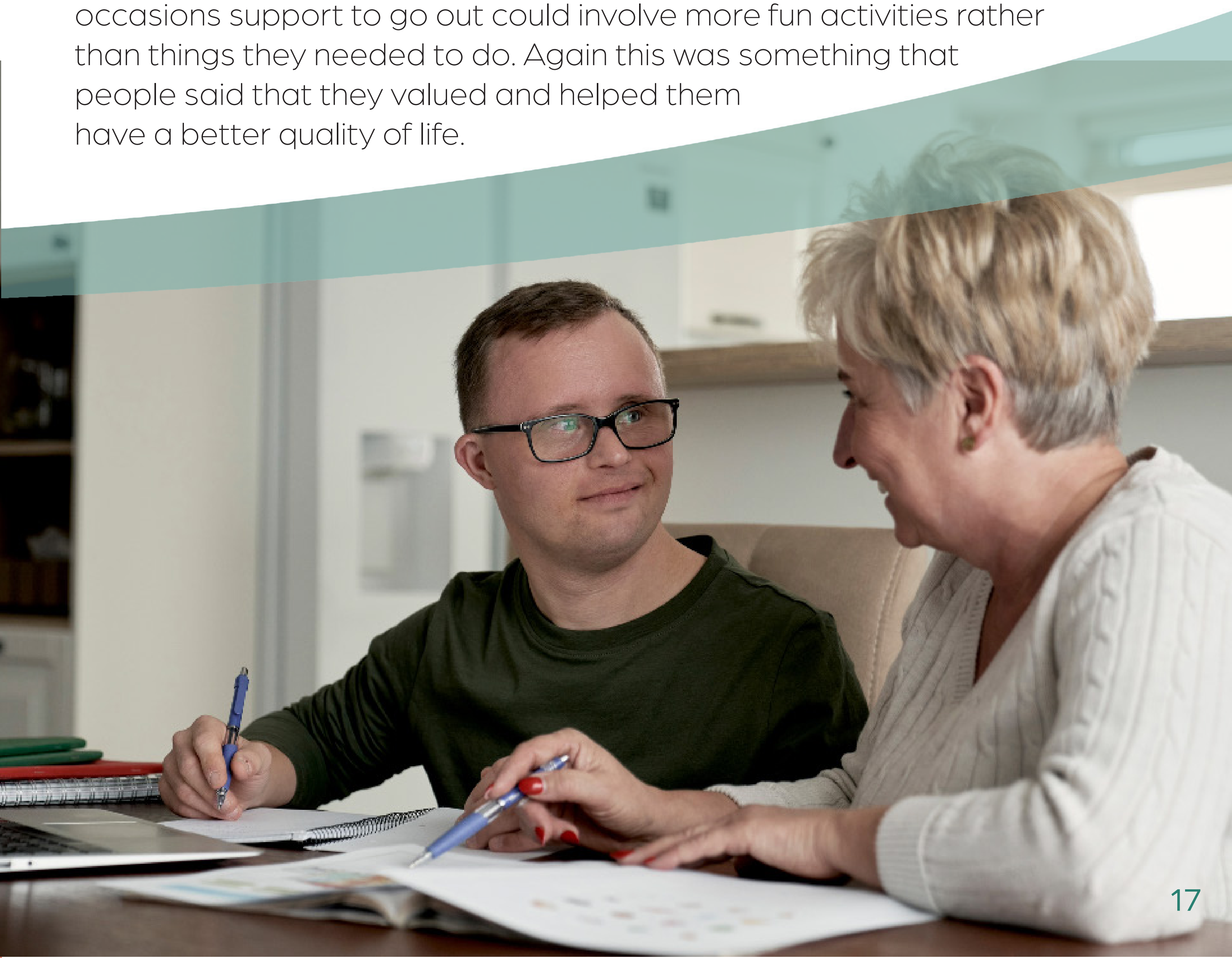
For some people, practical issues such as needing special pushchairs or wheelchairs could make outings more of an ordeal. Even if a person has no additional physical problems, there is a need to try to prepare for unexpected situations such as noisy venues, bright lights, crowds and other situations which can be very unsettling.

Lack of quiet spaces can make public venues very draining for people with learning disabilities. When faced with lots of difficult sensations, they may have bursts of loud behaviour or meltdowns and these can be upsetting for them, their carers and families.

When children need nappies beyond toddlerhood, or adults need incontinence support throughout life, this can mean that a lot of additional planning has to take place for outings. Many public places, even health and social care facilities do not have suitable changing spaces. This means people sometimes end up having to have nappies/incontinence aids changed whilst lying on the floor in public toilets or in other inappropriate places. There might also be more changes of clothes needed and washing facilities.

As children become adults this can be more challenging. Often people will cut short outings rather than dealing with the fuss and challenges of managing toileting. At worst, people avoid going places, simply because it becomes so difficult.

Many people in our survey valued having support to go out. Sometimes this was to go to places they needed to visit such as a hospital appointment and people felt this was far less worrying than having to go alone. On other occasions support to go out could involve more fun activities rather than things they needed to do. Again this was something that people said that they valued and helped them have a better quality of life.



Respite and carers

Respite care helps people with learning disabilities, their carers and families to have better life quality. It may involve a week away in a residential setting, days out or support to take someone on an outing or even time to do some indoor activities at home. People told us that this made a big difference to their lives and made them happier.

We heard that respite was not always readily offered. Relatives and friends simply might not be available to help or didn't feel that they were skilled enough to help. So, families and carers often struggled on alone without any external input, sometimes for months and years without having a break.

We heard that when regular respite care was available, this could be a huge help to families. It allowed them to focus more on other children or family members. It helped them plan for some rest and relaxation. It gave them a break from a demanding daily routine, and time to recharge their emotional batteries and/or physical energy.

We know that families often planned ahead for respite breaks because it gave them something to look forward to and helped them feel more resilient. But these opportunities were sometimes in short supply and could be cancelled with little notice when others needed to use respite care services because of an urgent crisis such as a family illness. People understood that this couldn't be helped but it could be very disappointing.

We were also told by families and carers that sending your loved one to a respite setting overnight, for a weekend or even longer could be worrying, even if it became part of a regular arrangement. A change in routine could be disruptive and it could take time for everyone to get used to new arrangements. We heard that some respite arrangements lasted for years and worked really well.

"The first family was lovely...we felt he was safe, looked after and cared for. Our child was doing well and joining in with activities. But then it had to change to another family, and it wasn't working out, there seemed to be odd things happening and we had to report it to the authorities."

People told us that when they had concerns about respite services, it could be difficult to make a complaint or raise these matters for discussion. People feared it could have a negative impact on their ability to access respite again or that their loved one might not be cared for so well.

"You want them to move on and grow up and become independent, but it's really hard to trust others to look after her. You get so used to being the person who does everything, it's hard to hand over some of that responsibility to someone else."

We also heard that respite support from carers coming in daily or a few times a week could be a great help. It gave the person with a learning disability some structure and routine for their week ahead. It allowed carers and families to plan some routine things for themselves like medical treatments or dental appointments.

We also heard that respite arrangements didn't always work if it was fragmented and inconsistent. If different support staff turned up each day at varying times this could be unsettling and disruptive. If there was a last-minute change of carer coming to the house or in an expected activity, this could have a big impact. Sickness with carers could also result in no support being available and could cause huge challenges. Families often found this really frustrating if it happened frequently because having a clear predictable routine could be really essential.

People also talked to us about the impact of having carers coming into their family homes. Whilst this was expected as part of the respite arrangement, it meant that there was a stranger in the family home, and there was lack of privacy for others in the family. Whilst mostly this worked well, there were times when it was a strain especially when it different people were coming into their home every day. This was described as unsettling, particularly if new carers or support workers became involved and had to be shown what to do and where things were kept.

Residential care

Parents and carers sometimes have to make profound decisions about long term residential care for/with people who have learning disabilities. This may happen as the person leaves education or training and wants to live independently. At other times, a change in living arrangements is needed because of illness, changes in family circumstances or a sudden crisis situation.

We heard that these were emotional decisions. If your loved one lives at home with you and has done for many years or the whole of their lives but then has to be accommodated elsewhere, permanently, this is a major decision.

People felt that in their dealings with professionals at these times, they felt that they were sometimes being given limited options about the places available. Sometimes there wasn't the opportunity to visit all potential placements, and it was exceedingly difficult to think about your loved one going to live somewhere that they hadn't seen before. We heard that staff commissioning permanent accommodation placements didn't always listen to families and only seemed to consider very few options and didn't understand the family's perspective.

Often these permanent placement decisions involved practical matters such as distance from home. This would impact on the number of visits that families could have. There would need to be consideration of the costs of journeys, time off work and accommodation costs.

Families felt under pressure to reach these decisions about accommodation placements. We heard that timescales were short and families felt that there was competition for scarce placements. Making profound decisions in a short time period was very worrying. Having, their loved one go to a long term residential setting far from home was described as traumatic.

We frequently heard that staff weren't always as supportive as they could be at this very difficult time. We heard how there was often a lot of paperwork to sign with little time to have this properly explained or to ask questions.

"I didn't realise that I'd given permission for my child to be restrained if needed. He had never been restrained before, it hadn't been needed and this was something I hadn't thought about."

We also heard that people's needs and preferences hadn't always been considered. Some settings were noisy, with frequent banging of doors in thoroughfares which could be very distressing. We heard that there wasn't always time to explore this properly before decisions were being made, so people were sometimes in rooms which were difficult for them to get used to.

Some families told us that their when their loved ones with learning disabilities were put into inappropriate accommodation settings, they would sometimes self-harm or try running away as a way of expressing their distress.

Often challenging behaviour or meltdowns were triggered by something such as different routines, inappropriate support or problems with the environment. We heard that this sometimes was addressed by restraint or medication and even police involvement. This often created very difficult situations for families when they had never experienced these difficulties before.

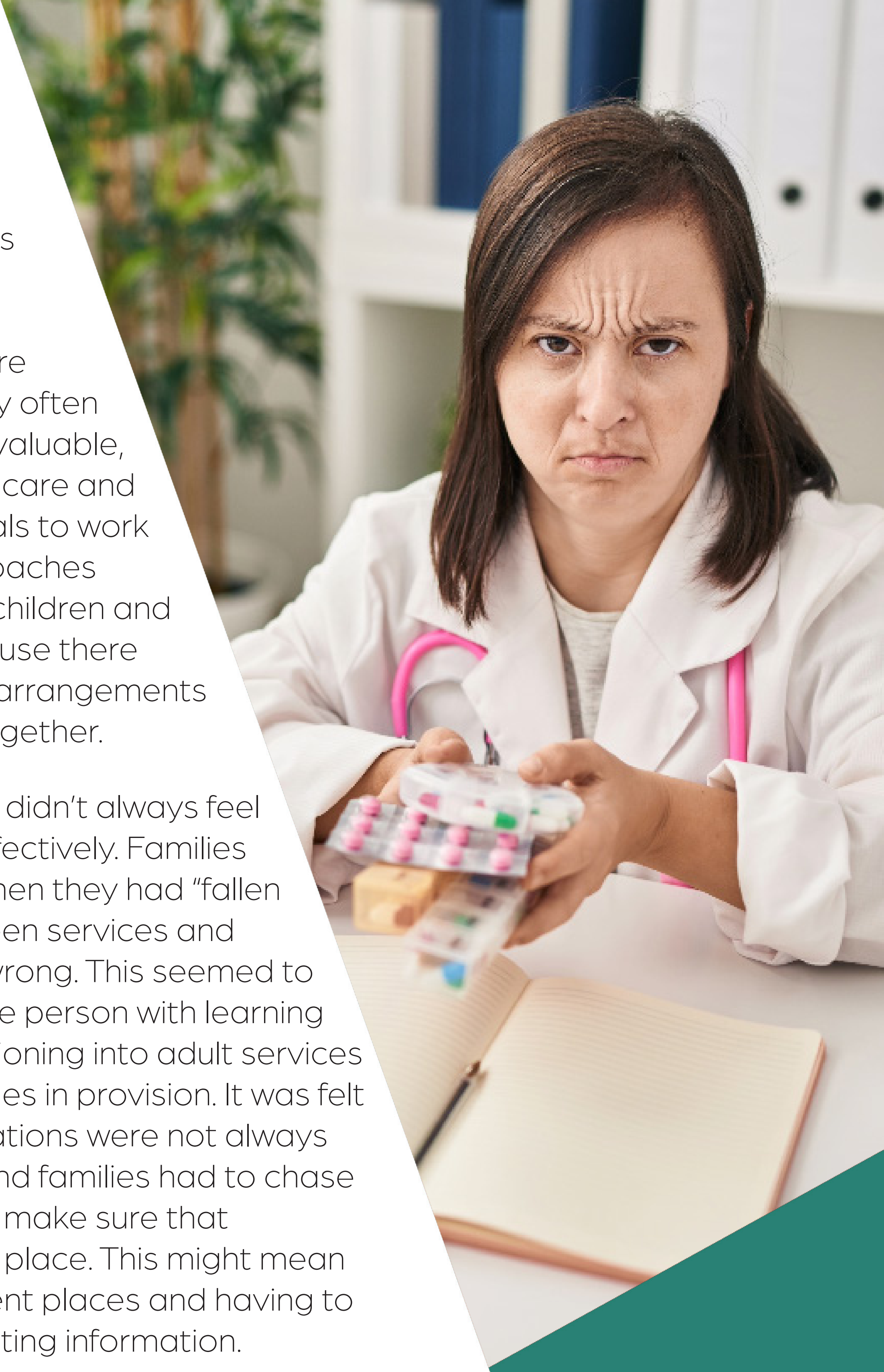
We also heard how sometimes communication was problematic when people moved into residential settings. Instead of speaking to their loved one daily, when they were at home, sometimes this had to change and they felt that they knew less about what was happening.

Families were often told without notice about meetings that were being held to discuss their loved ones' care and they couldn't always take time off to be involved. One mum was shocked to be told that her child was going to be sectioned under Section 2 of the Mental Health Act when she'd had no idea that his behaviour was becoming increasingly difficult in his accommodation setting.

Multi agency approaches

We heard from families who had also talked about multi agency approaches to the care of their loved one. Very often these were seen as invaluable, allowing health, social care and education professionals to work together. These approaches seemed to work with children and younger people, because there seemed to be robust arrangements in place for working together.

As people got older, it didn't always feel that this worked so effectively. Families told us about times when they had "fallen into the cracks" between services and things started going wrong. This seemed to happen more when the person with learning disabilities was transitioning into adult services or experiencing changes in provision. It was felt that different organisations were not always communicating well and families had to chase around themselves to make sure that arrangements were in place. This might mean multiple calls to different places and having to manage lots of conflicting information.



Using health care services

In our survey we asked people to tell us what it was like when they were using health care services. This could be any kind of health care service such as GPs, dentists, opticians, hospital appointments, mental health support and therapists.

We heard that these health care appointments often went well:

“They listen to me.”

“Doctors are very patient and take their time with me.”

“I am happy with all health care professionals.”

“They explained things so I could understand.”

“Have a community learning disability nurse who helps and supports me, doctor surgery do support me.”

“My mother comes with me to the dentist and to my cardiologist. My carers come with me to the GP. My GP is very good. He acts quickly if my carers think I’m unwell.”

“Friendly staff, felt listened too.”

“Recently I have 2 different female Locum doctors and they listen to me and help me understand.”

“I should say that I have NEVER had any difficulty with frontline staff, who have all been wonderful.“

We saw that staff providing healthcare were often described as patients and how people felt their needs were being met and they were getting help when needed.

People told us that when they used health care, that staff were patient, the environment was suitable and they got the assistance they needed.

“I managed to get an appointment with the doctor in two days and I have seen the doctor on the day of phoning for an appointment too at the Integrated Health Centre. The dentist was good and showed me how to look after my teeth.“

But there are some of the frustrations that we all face in accessing health care:

“Seeing dentist is impossible to get NHS one at all . Doctors as well you have to nearly beg to get to see. Hospitals you have to wait long periods of time to see a&e , and also appointment are also long periods.“

"Have to wait a long time to see orthodontist ......It is awkward seeing our GP because of waiting times and school disruption as a consequence. Optician and dentist are fine as they will see to an appropriate appointment time and see me instantly as an emergency if necessary. My foster carers have Denplan."

Other difficulties may arise because people with learning difficulties may need more time or different types of communication.

"Often difficult and frustrating. People don't adapt communication to help me. Appointments get cancelled and changed last minute which stresses me out a lot. "

People also told us when there had been improvements in the care that they were getting.

"now I have a better GP, he listens to me and gets tests sorted out."

"psychiatry has improved... "

People also told us when things were not as good:

“Prof Kerr’s epilepsy Ld clinic was a lifeline to so many of us – the health board took that away from us in June 2021.”

“Can be ok, depending on who you see.”

“Depends on the doctor, some good, some not so good.”

“Long waiting times.”

“Having to pay for dentistry as there is no NHS dentistry in the area.”

“The amount of time I’ve had 2 wait in the waiting room.”

“Waiting a long time/ eight hours at A&E; no food.”

“Too much noise, overwhelming, bright lights.“

We also heard that teenage years and transition to adulthood can be difficult in health care. When people are going through puberty and adolescence, it can create physical changes. Sometimes new and different health conditions arise as children get older and these can be difficult to deal with and involve different staff and departments.

“In the summer when he was sixteen, his behaviour changed and his epilepsy became worse. We tried to get some help but we were told he needed psychiatric support but there was no funding for this.“

People often tell us they felt let down by organisations that they thought would help them. This left them feeling disappointed and not knowing where to turn to next and sometimes no one seemed to know what to do.

“He had to be taken to hospital because of his seizures. There wasn’t a bed for him and there seemed to be nowhere for him to go.”

When there is no new help available and when there are changes in existing support systems, people with learning disabilities can become very unsettled.

We heard how medications could make a significant difference to people with learning disabilities, however medications have side effects which can cause more problems. People told us about medication for epilepsy which caused gum problems that needed more frequent visits to the dentist. Some families had assumed that people with learning difficulties would get free NHS dental care and when they found out that this wasn't the case, they worried about how they would pay. One family told us that they'd had to put a savings account in place for their loved one just to cover the cost of dental treatment because it could soon rise to several hundred pounds and possibly thousands.

We heard that medication was often a worry because some drugs could have an impact on behaviour and mood. Parents and carers told us that it wasn't always easy to get professionals to listen to them about medication problems and side effects. We also heard that sometimes it felt as if professionals weren't linking in with each other sufficiently about issues like medication. We heard that if Multi-Disciplinary Team meetings were held with the right staff involved, then medication management might be improved, and this would really be helpful.

We also were told that people often found it difficult when a person with learning difficulties became physically unwell. People with learning disabilities may have a particularly high threshold for pain or disguise their symptoms.

"We don't tell till its an emergency."

One person told us that they didn't like going to use health services and usually had to be really unwell before they went. This can make diagnosis of a physical illness more difficult.

"Doctor doesn't understand autism and responses to pain. Took a lot of training."

People with learning disabilities could often be regarded as complex, needing physical support, psychological and psychiatric support.

"We've had many challenges throughout his life, particularly with health, as the level of expertise and resources needed for someone of his complexity were very often not available."

Social care services

A number of people talked to us about social care services. We know that not everyone uses social care, and they manage without any input form others. Some people told us that they only had family members to help them because they had never had any other support. For some, they had never asked for it and didn't feel they needed it, for others, they didn't recall that social care support had been offered.

People who did use social care services told us that it meant that they could get help with eating, personal hygiene, money management, cooking, medication, mobility and daily tasks such as making a bed.

"I can go out with my support, I had fewer options at home with my family."

"They take me places I might not visit these places if I don't have support."

People didn't always know what kind of support was available and felt there should be more openness about care hours, transport etc. Others felt that this had been well covered with them and that they were managing direct payments and highly individualised care packages. People felt that there needed to be more independent supported living housing options.

Again we heard a mixture of opinions, both good and bad experiences of carers, social workers and day centres. For example we heard that day services were well run and that people liked attending them to see their friends.

" I have attended a day centre since age 16 until present day – now 57 years old. Always been happy and supported by staff, especially the key worker."

"I get 1:1 on Friday where staff take me where I want to go. Staff help me when I get overwhelmed or over stimulated."

Others were worried about having long term help because they'd faced changes in the past which had unsettled them. People were worried about the limited wages for carers and which meant that people moved into better paid jobs when they had the chance. They spoke about making friends with staff who then move on.

"I am with a care company and they are very professional but they struggle with recruitment and retention of staff which make me very unsettled."

Having the right people support you was important to people receiving social care. We heard that sometimes people didn't feel that they were well supported because there wasn't any cover available for them when their social worker was off work and this left them with a gap. Others felt that some arrangements were cancelled with limited notice.

People also told us that they wanted to be able to choose their own support worker as some were better than others.

"Not fully trained in my care plan."

Continuity of care was important because people could build good relationships with people who helped them on a regular basis. Where people took time to get to know them, care relationships worked far better.

"My carers are brilliant. They help me to be as independent as possible, and they understand my body language because they've known me a long time. (I can't talk – mum is writing this for me)."

Where things weren't going well people told us it was often because social workers or support staff were not listening to them properly.

"Social care don't listen about how I want my appointments. My preferences are ignored. I ask for at least 7 days notice for appointments and for it in writing but they sometimes just turn up at my flat."

Some people told us that they were being told to be independent when they needed support for particular activities such as travel because they don't live close to their family. We heard some people had concerns about not having enough respite services that could cover travel and this meant that they either didn't go places or had to rely on family members all the time. Lack of sufficient support in terms of travel often made people feel stressed because it might mean that they would be late getting to places because they'd had to manage alone.

Communication

Many people told us about good quality communication in health and social care. We heard that staff were usually patient and took their time.

"Let me use my words. Take time to answer and them not use long words I don't know."

Being able to see the same staff could make a big difference. When this didn't happen, people felt that they had to share their story again and again. This wasn't always helpful and it could be very tiring for them and it meant that appointment time was wasted.

People also told us that good communication could sometimes mean that more time was needed. If things were rushed, then communication could go wrong very quickly.

"I find it difficult because the appointments are so short and fast... and many of the doctors don't communicate directly. It takes me lots of time to process these things and often I've been ushered out the door without a satisfactory outcome. For example, I went to the doctor for a very painful hip condition and he told me I could take strong anti–inflammatories for it. I said 'I have been taking ibuprofen'. He said 'in that case if that's been working I won't prescribe you these stronger ones'. I was very confused, but it took me until I'd left to realise that he had interpreted my mention of ibuprofen as successful pain management. I was simply adding it as an additional piece of information. It was not working for me....but he'd already decided not to give me the stronger ones........so the next doctor I saw, months later, did."

We were also told that sometimes, information isn't always shared. For example, we heard that people with learning disabilities didn't always know about annual health checks and hadn't had a check simply because they didn't know about it. Those who did know about annual health checks found that GP surgery staff weren't always familiar with this entitlement.

When patients phoned up to ask for one, they found it stressful to have to explain they were entitled to have a check and it was difficult sometimes being assertive. For some, extra arrangements had to be made and they found it hard to get an annual health check when they are housebound or in places other than the GP surgery.

When appointments with health and social care services were needed there were also areas that could be improved.

"Must only discuss one condition and use special words I don't know to explain. I've many illness and easily overwhelmed."

"dentist hygienist not neurodivergent friendly – always critical."

"Dismissive nature and lack of general understanding of conditions and their effects, sensory overload, lack of processing time, time pressures."

*"I also often have lots of questions.
Sometimes they get defensive when I ask questions...
but I only want the answer, I'm not trying to criticise them."*

"Sometimes a lack of GP understanding. I always need someone with me"

"Feeling like I'm not always listened too. When I go on my own I'm not too good at remembering or understanding things"

Where communication is a significant issue in health and social care provision, this may sometimes mean more education and training may be needed. At other times it was identified that there was a need for more easy read letters and information that people with learning disabilities could understand without needing to ask for help.

Getting older with learning disabilities

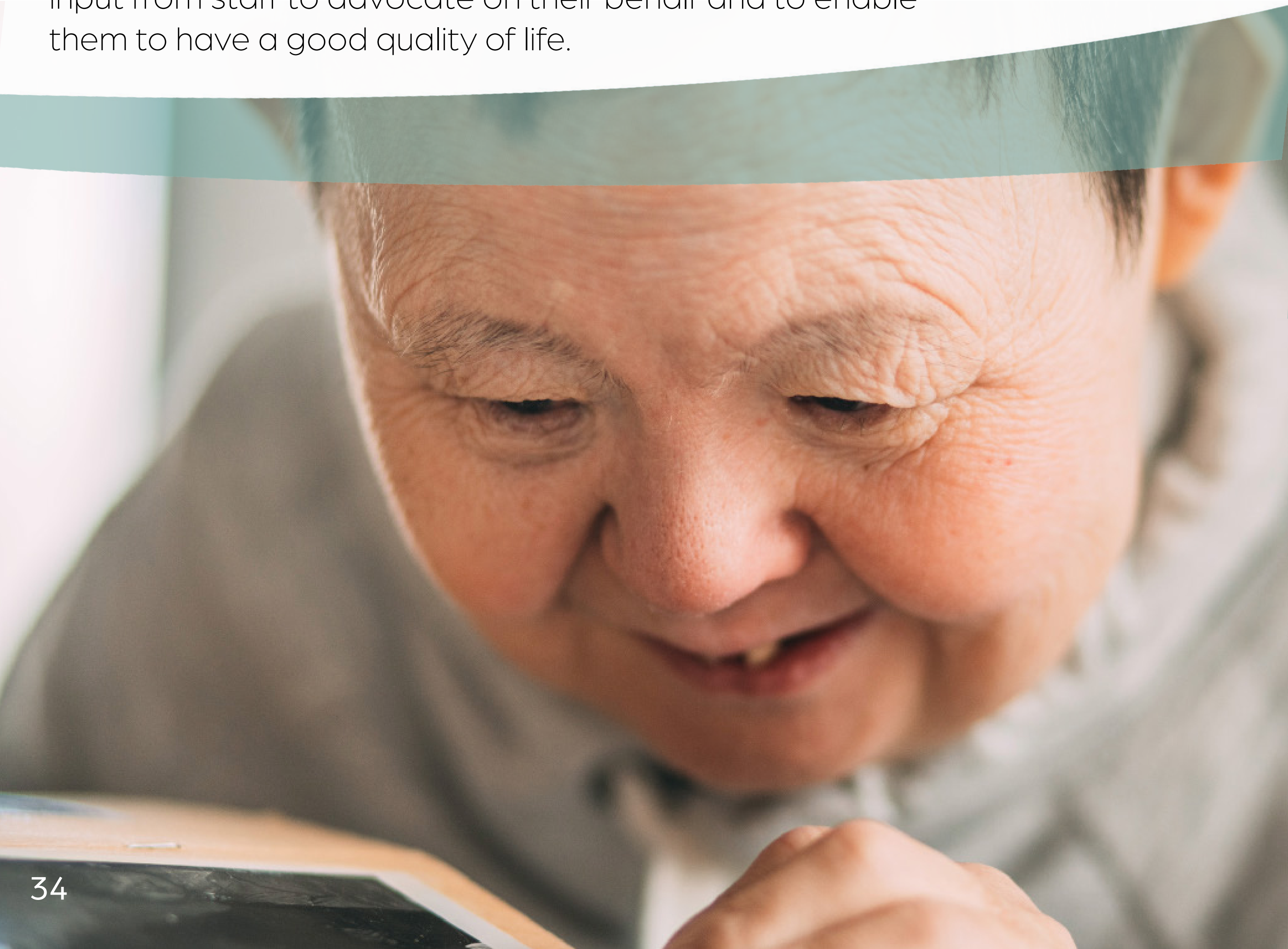
We didn't hear from many older people with learning disabilities during our project. But we know that as people get older, they may often need certain types of health care such as cataract surgery, menopause clinics, breast screening, bowel tests hip replacements or end of life care.

They may also need more support with daily living activities because they are less physically able to do things for themselves.

We don't know how well this works because we don't have any stories about these kinds of issues yet, but we hope that people will talk to us about this. We know it is important that services for older adults need to be able to provide good quality support for everyone, including people with learning disabilities.

Although we didn't hear from people with learning disabilities or their families directly on these matters, we did hear from people who worked in care settings that provided long term care to residents with learning disabilities. They told us that sometimes their residents may have lived in that setting for over 30 years but as they got older, often they needed more care input. This might sometimes mean that they would have to move to a different kind of care provision and this could be unsettling for people at the end of their lives.

They also told us that as people with learning disabilities get older, they often had less family involvement. Parents, siblings or other family members might have passed away or be unable to visit because of their own health conditions. Again, this risked people feeling isolated and needing more input from staff to advocate on their behalf and to enable them to have a good quality of life.



When things don't go right

When things don't go well with health or social care and if a complaint is made, this can be really worrying for people with learning difficulties and their families. This is because people still need to be using and accessing services whilst complaint handling procedures are being followed. People can feel very isolated and may sometimes feel that they don't have the time nor energy to complain.

People worry that their care may suffer if they express dissatisfaction and significant decisions made by professionals about them may be affected. We have heard that sometimes people are too worried to make complaints.

We heard that for people making complaints, that relationships with staff can become very difficult, distrusting and antagonistic.

"I am also quite concerned at the recent decision to merge inpatient LD and MH adult services – this seemed to be characterised by a significant lack of communication, and I'm not convinced that our voices were heard in the consultation."

"The difficulties we have had have been with commissioning decisions, lack of communication on the part of senior managers."

"There was a failure to provide necessary psychology services, so his clinical needs were not met."

Thank you

We thank everyone who took the time to share their views and experiences with us about their health and care services and to share their ideas.

We hope the feedback people have taken time to share influences services to recognise and value what they do well – and take action where they need to do things better. We don't just undertake a piece of work and then move on to something else. We're always keen to hear about people's experiences that link in with work we have done in the past so if you have something that you want to share with us, please contact us.

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