

# Do disabled children and young people have equal access to education and childcare?

Children, Young People and Education Committee

Engagement Findings

March 2024

## Background

The Children, Young People and Education Committee is conducting an inquiry into childcare and education access for disabled children and young people and the extent to which childcare providers, schools and local authorities meet their duties under the Equality Act 2010.

The Committee would like to understand how children and young people who are neurodivergent and have physical, sensory or learning disabilities can access all aspects of education and childcare.

To ensure lived experience is central to the evidence the Committee heard, the Citizen Engagement Team proposed a qualitative approach to the engagement.

## Methodology

40 engagement sessions (*Family interviews* hereafter) with parents, carers and occasionally, children were facilitated.

Family interviews were conducted virtually and face-to-face.

The sessions lasted approximately an hour. When children were involved, a game of Jenga was made with keywords on some of the pieces. As the words were discovered through playing games of Jenga, the children were asked questions about their experiences.



Using the discussion guide as a framework (see Annex 1) the facilitator explored the reasoning around what participants were saying by asking non-leading questions.

Following each family interview, an anonymised, verbatim note was written.

## Sample

Several organisations and charities that are already working with families who might be eligible to take part were contacted by the Citizen Engagement Team.

A list of the organisations that circulated the opportunity to take part with families is listed in Annex 2.

Organisations were asked to circulate the opportunity and families were invited to contact the lead Citizen Engagement Manager directly if they wished to take part. Participants were self-selecting.

59 families contacted the Senedd expressing an interest in taking part.

40 families took part in family interviews (42 adults and 17 children in total)

Participants were from 20 of the Welsh Local Authority areas.

## Key Findings

Below are the key themes which emerged from the data, that include inclusion, access, and impact.

### 1. Inclusion

In assessing a child's educational needs, it varies by school; not all meet requirements for disabled children. Many interviewed families switched schools to find adequate support.

#### Unfair treatment

Common themes discussed about inclusive education included unfair treatment, with instances of harassment and discrimination against disabled children in schools, sometimes unintentional.

*“They sent a letter home to invite children in his year to learn the violin. We didn’t get that letter. It wasn’t until I was coming out that he said “May...violin..me” I inquired and the staff said the auditions had closed. I insisted they consider him and so they agreed to an audition. The person supporting him for the session had never played a violin in their life, and the*

*woman came out from the county and said he wasn't good enough." - Parent of a child with two progressive genetic diseases.*

A parent of a child with Down syndrome explained there had been an incident of social exclusion in the primary setting where their child had been banned from socialising with two other pupils. *"The teacher said it was because the other children needed to build relationships with typical children in the class. [...] I was devastated and felt acutely that my child was [treated like] a second-class citizen. [...] some teachers get it and some just don't. With any discrimination, I'm sure there are pockets, we are definitely making progress but it's still happening."*

A parent described how their autistic child would be asked not to attend school because they did not have the staff, despite the school being funded for staff to support the student. *"You feel singled out, because if you are the only one getting a text saying don't bring your child in tomorrow, it feels wrong. Those things have never happened to me with my other child who isn't disabled [...] it was a massive form of discrimination"*

Parents feel their children lack equal opportunities. One parent noted a stark difference, emphasising that leaving neurotypical children without a teacher for 30 months would be unthinkable. Another parent, with a child with Down syndrome and two non-disabled children, highlighted the ongoing fight for equality, acknowledging efforts by the comprehensive school but noting that choices have not always been equal.

#### **Issues with support from local authorities:**

There was a general lack of trust in the local authority

*"I generally feel that some of the things the council tell you are not truthful." - Parent*

Parents felt that many of the decisions were financially driven.

*"I kept thinking, I don't know whether you're saying this because you've got my daughter's best interest at heart or whether there's another agenda."*

Parents often attended meetings without consideration for their feelings or adequate preparation time. They felt caught off guard, pressured, and sometimes intimidated into agreeing with education professionals due to a lack of knowledge about alternative options for their child.

*"I thought I was going in for a review, but it was a big meeting, where I was given an ultimatum." – Parent*

A parent of a nonverbal autistic child had no choice but to send their child to a specific school, labelled as a last resort due to funding limitations. They were excluded from an open day, which made them feel like second-class citizens.

Some parents noted a lack of basic communication from professionals, wishing for clear outlines of roles and available help. Parents were uncertain about finding suitable schools and felt unsupported by the local authority when seeking better provisions for their children.

*"I couldn't get hold of anybody, it took me eight weeks to find out that they couldn't advise me, I was told I just have to go and find that out for myself." - Parent*

*"I find out information from families alike, not from the people who are meant to be delivering and offering these services to you – the local authority."*

A family with a child with a brain tumour learned about a specialist school through word of mouth, not from the local authority. The process took 9 months, and the child attended for just over a year before becoming too ill. The parent expressed regret, stating that knowledge of other options earlier would have prompted them to explore potentially better alternatives for their son.

### **Labelling stigmatised disabled and neurodivergent children:**

*"They always say it's like he's naughty, but that upsets me because it's not naughty, it's because he's autistic." - Parent*

Parents noted a lack of understanding of certain behaviour, leading to labels such as "naughty," "violent" and "requiring extra supervision" for their children. Such labelling exacerbated issues and, in some cases, had a detrimental impact on their child/children's mental health.

*"A lot of approaches to discipline were generally quite shaming and punitive. I remember in nursery, they had all the kid's faces laminated on a display with a rainbow and a storm cloud, and if the child was "naughty" they would move your face to the storm cloud. You would never put that display up in the staffroom, that would be classed as bullying in the workplace. Why do they*

*think it's okay to do it to children?" - Single adoptive parent of a child who has experienced significant trauma and adverse childhood experiences.*

*"Knowledge, experience and funding are the things that stop schools and nurseries from providing inclusive education. For example, the nursery sometimes categories my child into a box, and they need to be more open-minded about what autism really is." - Parent of a child with epilepsy and suspected autism.*

### Access to Welsh medium education

Many parents talked about issues accessing suitable Welsh medium education provisions from a range of ages.

*"He's never been afforded Welsh education – because he's deaf. They wanted to disapply him from history, geography, and music. They said it's not accessible."*

*"They [the children] are not speaking to me in Welsh. I was advised to stop teaching them. The speech and language therapist told me to choose a language. [...] I was devastated, I grieved. I'm working through the medium of Welsh, I cried for days." – Parent of two children with multiple complex needs*

The parents of a child with uncontrolled complex epilepsy noted that their child does not have the same choices as others in terms of Welsh medium education. Some of the options offered to their child for secondary education mean receiving an English-medium education, even though Welsh is the child's first language.

### Support during the Covid-19 pandemic was generally perceived as similar to what all children accessed

*"I don't think there were things that my son missed out on other than what all children missed out on." - Parent*

Children described their experience of education during the Covid-19 pandemic as "fun" due to the absence of school, which they described as "boring". They expressed enjoyment being able to do school work in bed. Furloughed or homeschooling parents created successful life skills, play-based learning programs with virtual support from schools. However, some parents, due to their circumstances, experienced difficulties establishing an environment which was conducive to effective homeschooling.

### Exclusion from residential trips

This was raised as an issue by some families. They outlined how their children had not had equal experiences of day trips or residential trips.

*“Residentials are not accessible to my son. There’s no breakfast club, there’s no after-school clubs and even now there is no summer school. There is nothing extra for those with complex needs.”* - Parent of a child with cerebral palsy

*“He was excluded the day before the school trip. I questioned if this was intentional after everything that has gone on.”* - Parent and a child awaiting a diagnosis of autism, attention deficit hyperactivity disorder (ADHD) and Pathological Demand Avoidance (PDA)

However, some families also said the schools had worked hard to make sure they planned well and supported their disabled children.

## 2. Access

### Prolonged diagnosis journeys

The route to diagnosis was varied for participants. Many parents talked of how they had endured a long wait or had decided to get an external diagnosis to enable access to support more quickly. This came at a financial cost.

*“We’d have been in crisis if we had waited 18 months for the NHS to complete the diagnosis.”*

*“You’re told that unless there are “real problems” they can’t test or check. The school didn’t pay for that anyway because we decided to pay for that with our own money in the end [...] I paid £650 for a dyslexia assessment, that’s why it took ages to be able to afford it.”*

Some parents felt because they had a prenatal diagnosis, they might have had access to support more readily but access throughout the child’s education journey was not always a foregone conclusion.

*“I found the first refusal astounding. He’s got a lifelong condition that he’s going to need support for his education. [...] I had a fair bit of a challenge to*

*get 100% support for my child, I had to fight them for that.”- Parent of a child with Down syndrome*

Some parents described how schools had made allowances where they could identify a pre-diagnosis. However, without official diagnosis, they were unable to offer more support due to funding constraints

*“The school have been amazing and has acted before diagnosis.”*

In most cases, a lack of diagnosis meant a lack of access to support in an education setting and gaining a diagnosis was something the school needed to instigate. This was described as “tricky” by some parents who said they felt that their children were masking their true selves at school, but could be themselves at home.

Quotas to put children forward for a diagnosis were described as limited. Some parents wondered why staff could not be part of this process to enable things to move more quickly.

*“Schools have Additional Learning Needs Coordinator’s and I believe they should be skilled up to be able to diagnose the children themselves.”*

Parents said they were abundantly aware that every day their child lacked the support they needed, was another day they were not getting a full education.

*“Just waiting for the support that he now has to be in place has taken so long and he’s missed out on so much, he’s encountered some tough times and it’s made education negative for him. He talks about not waiting to be alive any more, and when you hear your ten-year-old son saying that it breaks your heart.”*

Many parents said how they thought that getting a diagnosis would mean the local authority signposted information automatically but this tended not to be the case for many families:

*“After diagnosis, I thought a million things would come at me to offer help, unfortunately, because of our local authority I haven’t been offered much at all.”*

Unfortunately for some children, the delay will mean diagnosis will come too late to have an impact:

*“He’ll leave school before he gets a diagnosis.”*

### **Inadequate health services that are required to support children to access education**

Access to services like adequate speech and language therapy, and occupational therapy were repeatedly listed as initiatives that would enhance accessibility and inclusion in education.

*“SaLT [Speech and Language therapy] is a big big issue [...] My child might never speak but we can't just expect her to get on with it..” - Parent of a child in early years with a diagnosis of epilepsy and suspected autism.*

*“I feel like the speech and language provision is lacking and education and health keep throwing it back and forth as to who is responsible for this” – Parent of a child with a rare genetic condition causing physical and cognitive disabilities.*

Seating support for a child with spina bifida was deemed dangerous by the parent. Despite the educational psychologist's request for a floor seat, the occupational therapist insisted on propping the child against an old radiator. The child, unable to use hands like others, faced difficulties. The occupational therapist declined assistance with technology, claiming it was not their responsibility. It took considerable effort for the parent to get the child properly examined, with school's referral lacking medical details. Parents expressed frustration with repeated staff changes.

*“He's seen three different speech and language therapists so far, and he's two years old.”- Parent*

*“There was no communication and when one SaLT left and another was recruited, my child didn't see a professional for support for 6 months.” - Parent*

A parent of a child with a brain tumour criticised NHS physiotherapy services for lacking goals and they also felt services were limited due to not backfilling maternity cover. Another parent with a child with cerebral palsy expressed concern about how large class sizes meant there were limited NHS physiotherapy services shared out among the students. They expressed concern that their child was not receiving adequate care.

Parents of a child with epilepsy and suspected autism were dissatisfied with the development team's inaction over two years. The development nurse, speech and language therapy professional and occupational health professionals, make up the development team. The team merely assessed the child's abilities without providing support or referrals, leaving the parent to address safety concerns by strapping the child into a buggy. Access to essential equipment like a wheelchair was denied, despite the parent's plea based on safety reasons.



### **Style and structures within schools are not designed for all:**

Participants acknowledged schools' role in education but highlighted a tendency to overlook mental health resilience. Many emphasised their children needed more support with social aspects, yet academic assessments were predominantly unsuitable for many disabled children. In one session, the parent of a five-year-old awaiting an autism, ADHD, and PDA diagnosis expressed the need for greater expertise in recognising certain behaviours over academic work.

*“For my child, she began to “not fit” in as the GCSE curriculum started. The being singled out, educated separately just became more and more and more the norm.”*

*“The focus is always on “we need to adjust this child” not “we need to adjust our practice”.” - Parent*

Some teaching styles meant that some parents felt their children were not being challenged enough in school because the teachers were not designing tasks, which were suitable for their children. The school was described as pacifying the children rather than aiming to adapt their activities to make it easier for the children to take part.

*“I question and worry that the school are going over and over the same things that are nursery level.” - Parent of a child with cerebral palsy*

*“They wouldn’t normally send a 10-year-old to play with 5-year-olds. But I guess that they are doing it when they are short-staffed.” - Parent of a child with Down syndrome*

Disabled children were often segregated, receiving one-to-one support from a teaching assistant instead of the teacher. This led to a disconnect between the person setting the work and the child's actual level, as they lacked regular interaction with disabled students. In an engagement session, a child expressed that teachers were unaware of her disabled sister's abilities. During lockdown, her sister, in high school, received overly easy work compared to the child's primary-level assignments, indicating a mismatch in the difficulty level of the tasks.

### **Lack of understanding mainly attributed to a lack of training:**

*“It’s not been an easy journey to get them to understand that it’s a disability and we need to treat it as such.” - Parent*

The parents described how they felt that their children were set up to fail every day because the schools were not willing to make reasonable adjustments. They also said they felt that schools were not fully aware of the range of disabilities due to a lack of training.

*"I asked for a freedom of information request at her last SEN school to find out how many teachers are trained in PECS [Picture Exchange Communication System] - not just a PECS awareness course, but the PECS Pyramid Education qualification and the answer was zero - my daughter was being trained PECS by people that aren't trained themselves. I was astounded." - Parent of a child with a genetic condition*

*"When he's had a consequence (a punishment) the first thing they do is take his play time off him. For a child with ADHD that is just going to make the problem worse." Parent of an autistic child in mainstream primary school*

Some participants explained that issues were exacerbated due to lack of expertise and consistent staffing.

*"I think an ALNCo should just be an ALNCo. Especially when you've got over 1000 kids in your school." - Parent*

*"The ALNCo didn't have any experience and they were just learning on the job." - Parent*

An autistic child in one of the engagement sessions was surprised at the lack of enthusiasm by some teachers to receive more training:

*"Some teachers don't want to admit that they aren't fully informed or fully trained. [...] Teachers should be open to learning new things too. [...] If teachers refuse to educate themselves, which many teachers actually do, and then the students will follow by example and this means the whole school becomes a toxic environment and therefore isn't inclusive to all children." - Autistic child*

A shortage of staff trained in self-care and toileting needs hindered many children from attending mainstream education, irrespective of other school provisions. A parent of a child with a brain tumour worried about staff dealing with potential soiling incidents during mainstream education, fearing they would just call the parent. This lack of flexibility concerned the parent, as the child's physical needs might go unmet.

Another parent, with two children with physical disabilities, had to fight for access to running water for medical care at school. Multiple staff supporting the other child with toileting raised safeguarding concerns with the parent.

*"I was accidentally given the bathroom file showing no nurses had been visiting and over 14 members of agency staff were going back and forth with my son to the bathroom."*

#### Limited opportunities for parent voices to be heard:

*"As a parent, I feel like they (teaching staff) go out of their way to keep you at arm's length because they think if you say something to them it'll create work – there needs to be a mentality to be inquisitive and want to understand but I realise they are limited on their time." - Parent of a child with two progressive genetic diseases*

Parents often expressed that they felt like they were not being listened to, even though they were their child's strongest advocate.

*"From about 18 months old, I have had to fight for everything, even just to get her seen, and no one was listening." – Parent of a child with epilepsy*

*"They see parents as the problem [...] No one really listens." – Parent*

A parent with multiple children having diverse needs expressed minimal trust in the local authority concerning their children's education, describing it in negative terms. The parent said they felt their views were disregarded, emphasising that professionals do not genuinely consider their child's needs. In cases where children mask their needs at school, parents have faced barriers accessing support. Some participants discussed feeling gaslighted, with professionals dismissing the importance of one-to-one support. This was seen as disingenuous and unprofessional, as parents understood the necessity of supervision in various settings.

*"We are supposed to be considered when the IDP is being put together but they literally do not care, they don't care that we have experienced so much and we know what is going on." - Parent*

*"The school said we need to modify his behaviour, and I explained he is autistic, but he was restrained every day that he went into that school. I explained that we've never restrained him at home and he's been with us for seven years. Some staff actually spoke to me outside of the school and said they felt that restraining him was inappropriate. He came back with so many bruises and fingerprint marks and I was told I was just being precious and looking for things." – Foster parent of a child with spina bifida.*

## Lack of all-year-round childcare, wrap-around care and support during school holidays

*“There are no equal opportunities for childcare over the summer holidays.”*

Parent of a child with Down syndrome

*“There is NO childcare facility provision !!!!! I have NO choice!!!! The limited number of spaces over the summer is not even a choice it’s a lottery [...] Even if I was rich there is no facility in my local authority area that I can, out of my own choice, send my children to for the level of childcare that my children need.” - Parent of two autistic nonverbal children with complex needs.*

Parents outlined inherent issues with access to childcare for disabled children. Participants said that in most areas of Wales, there is no facility willing to take on disabled children:

*“Children over 5 years old in my local authority cannot access childcare. They say that the parent can access funding to go to a nursery, but the nurseries cannot provide the provision to look after children with ASD who are nonverbal and who have a high level of complex needs. [...] One of my children strips, the other might be pushing clothes down the toilet and flushing it. Our children need constant one-to-one supervision.”*

Another parent of a child with cerebral palsy said:

*“Routine is the ultimate thing when it’s disrupted then by the six, well it’s more like seven weeks holidays, it’s so challenging. We were hoping to access a summer school through the special educational needs unit but this was actually removed and the local authority refused to fund it.”*

Parents felt that continuity in delivering childcare provision across the year would be helpful:

*“I can’t tell you how much of a negative impact the school holidays have on my children. The ideal situation for me would be, if the parents want to take the kids out of school for a holiday any time across the year, just let them do it. Because any break upsets the sleep routine and the clothes they wear. I understand that teachers also need a break but maybe they also take holidays at any point. This would be massively helpful.”*

Parents described the feeling of not having access to childcare as discrimination. They explained that being unable to access childcare meant they were unable to work and have to give up on their careers. They explained that this was not optional.

*"I have another child without a disability and I can just click a button and she can be in a camp for six weeks over the holidays. It's as simple as that."*

### **Inadequate communication**

*"Lack of communication is the norm in every school he's ever been in." Parent of an autistic child who had been in four schools.*

Some parents described finding out that their children were struggling during parents' evenings. Sometimes this was too late for them to intervene and support their children to catch up.

Parents raised concerns about inadequate communication from school staff regarding the daily experiences of non-verbal students. They called for robust systems to convey essential information such as healthcare details and bowel movements that the children could not communicate.

Additionally, there were worries about the safety of their children, with concerns about a potential increase in physical abuse within school settings.

*"My son was bitten and the school didn't even know about it. And this kind of stuff happens all the time."*

*"When I rang school because my son had been placed in a headlock by another pupil, the ALNco seemed surprised that I had called the school about this."*

### **Inadequate access to resources linked to perceptions of a lack of funding:**

Parents spoke positively about the school and stressed that it was not the school that was unable to meet their child's needs. Often it was the local authority who would not fund a staff member to support the child in a mainstream environment.

*"The school are doing everything they can. It's the local authority that don't want to do anything to help at this point."- Parent*

*“Some schools are better at adapting but money is a barrier to being more inclusive [...] a lot of schools would be prepared to do more if they had more in their budgets.” - Parent*

One parent with a child with Down syndrome felt inclusion *“needs to be based on the needs of that child, not on how much money is available. Everybody has a right to an education and to achieve the best that they can.”*

### **Reduced timetables:**

Children with disabilities often face reduced timetables, receiving fewer educational hours than their non-disabled peers. While the justification is often framed as the child's inability to cope in extended settings, many parents suspect the real cause is the school's limited staff numbers.

*“They only wanted her from 9-12 o'clock but I said no because no one is helping her. They have said she's severely behind, and her being at home for half a day is only going to make it worse.”- Parent of a child diagnosed with global developmental delay*

Some parents described this as *“constructive exclusion.”*

Where children are expected to be at home for extended periods, parents have struggled to access suitable (if any) work for their child to do from a home education setting.

*“There's no help out there, I asked the teachers to email to share themes and topics – I have to wing it!” - Parent*

A parent of a child in early years education, awaiting an autism diagnosis, explained they have to take their child out of the school setting for 30 minutes during lunch. This was due to the school's inability to fund staff for lunchtime supervision. The child misses out on social aspects during this break while peers remain in school. The child then re-enters school for an hour and 25 minutes on a reduced timetable before finishing the day.

### **Poor processes to access support**

The system of accessing support was described as testing and not appropriate for people who are already under undue stress:

*“You feel like you are playing a game but no one explains the rules to you” – Parent of a child with Down syndrome.*

*“The questions on educational assessment are very open and when you are dealing with the day-to-day stress of supporting two disabled children, particularly one with a life-threatening illness and another that can be very unpredictable you don’t have the headspace to “blue sky” think about it. And you are threatened with “if it’s not in this paper then it won’t be addressed” – Parent of two disabled children*

Parents had concerns for all children as they felt there could easily be parents who were unable to fully access support due to the constant barriers and challenges. Information was not described as accessible.

*“Parents are out on a limb if they aren’t well informed and not aware of all the things available. It’s unfair if you don’t know the system. [...] I know where to look for information but for some parents, it’s so daunting.”- Parent*

### Transport services varied in quality but often weren’t flexible

*“He had a statement before the diagnosis, and he was part of a mainstream school and, I found out about disability allowance, nobody told me, the transport was never mentioned.[...] I wasn’t able to even park in the school car park and some days I had to park up out on the road and carry him into the school.” - Parent of a child with two progressive genetic diseases.*

The parent of two autistic non-verbal children with complex needs described how transport has not always been perfect. At one point, the taxi company had to also transport a physically abusive child and this became a problem.

*“Nothing was done until one day the children came home hysterical because they had been hit and had their hair pulled out and I complained and said I didn’t feel that they were safe. Transport always wants evidence. It’s disgusting that they don’t listen to what you say. I had to put my children in a taxi with this child until they were violent and until that point, nothing could be done. [...] I feel that money is placed above the welfare of the child in the scenario of transport.”*

Several parents faced challenges in securing adequate transport, leading them to drive their children to school and stay nearby until pickup. When organising transport for one school, a parent attempted to arrange an introduction for the child, driver, and escort. The transport company's reassurance that they were "used to dealing with people that aren't normal" horrified the parent, prompting them to decline the transport.

Transport lacked flexibility, resulting in one child arriving at least 20 minutes early due to accommodating another autistic child, highlighting the impact of limited school placements. Another parent battled with transport services that refused to deviate from the "home to school, school to home only" policy, even though the parent was willing to pick up the child from the nursery, leading to a significant struggle.

### **School environments are not conducive to disabled and neurodivergent children.**

Parents identified oversized class capacity, harsh lighting, busy display boards and crowded spaces as factors which are not always conducive to creating a suitable learning environment for disabled and neurodivergent children.

*"If a school doesn't look like it can be accessed then a parent is going to disregard it as an option for a disabled child [...] unless you can imagine your child in a school, you aren't going to even knock on the door."*

Parents felt that co-production when designing school buildings was imperative.

*"When plans and designs aren't co-produced they are rarely fit for purpose."*

Furthermore, because of overstimulation and/or exhaustion, disabled and neurodivergent children have been segregated:

*"During my son's last review in the mainstream school, it showed how he wasn't spending any time in the classroom because it was over-sensory. He struggled with more than 2 hours in the classroom per day. But the school didn't have a quiet room or any space to take him to so he was mostly spending his time in the corridor in his wheelchair. That was all the school had at their discretion."*

A parent of a child with cerebral palsy highlighted the lack of wheelchair accessibility in most local authority schools, noting the absence of facilities like a changing bed. Planning journeys involves changing the child before leaving, even for hospital visits. Some parents emphasised a gap in provisions, with options available for severely disabled or neurotypical children but lacking support for those in between.

*"There are 'in-between children' who are really struggling and no education facility is available to them."*



### 3. Impact

Themes regarding the impact on people with lived experiences when unable to access childcare and education repeatedly included terms like "battle," "fight," or "struggle" to describe their experiences. The extreme pressure on families was evident, and the use of this terminology was intrinsic to their discussions, reflecting the tone set by their lived experiences.

*"It's so wrong that you have to know so much more than them [local authorities] to be able to fight for the provisions that are suitable for your child [...] it's always a fight and it shouldn't be this much of a fight for everything."*  
Parent of a child with cerebral palsy

A parent of a child with a genetic condition described the role of each "Mum" of a child with Additional Learning Needs as an "army of one." These parents are constantly fighting on various fronts to uphold rights. While they may share similar experiences, the battles are unique due to each child's differences, placing the parent in a position of fighting alone.

#### Employment for families with a disabled child

*"It was as if the school didn't think that I was employed. They expected me to look after my child when they overnight decided they couldn't have him in the school."* - Parent

Parents repeatedly described how it would be impossible to work in the situation they were in. Some were able to work but they might have taken lower-level jobs or become self-employed so they could work around childcare. This was described as a 'juggle' (particularly in the summer holidays). Parents said:

*"I feel like I'm not allowed to have a career. A charity said to me "Have you thought about not working?" would they say that to my husband?"*

*"There's no incentive to work, because there's no support, there's no childcare. They are creating a problem by not creating childcare."*

#### Mental health and wellbeing impact:

Disabled children's mental health varies, linking to access to education or childcare. A negative school experience contributes to anxiety and attachment issues. Children feel

left out due to special needs and teachers' lack of understanding. Some report social isolation and difficulty making friends without sufficient teacher support.

A deaf child who generally has good mental health, occasionally feels lonely as the only deaf student. Parents note delays in addressing mental health by schools and services, with many on prolonged waiting lists, even for crisis care.

*"He's told school staff that he's had suicidal thoughts and we've been put on a waiting list which we have been on for two years now."*

*"We did reach a crisis point eventually, and I was referred to the crisis team, but they have a waiting list of six months. [...] I got a referral after I refused to take my child home because I couldn't cope. That's when the school recognised that I needed support."*

Poor mental health affects entire families. One parent, exhausted from constant battles in the education system, anticipates relief when their child is out of the system. The toll on parents includes stress, anxiety, and sleep deprivation. Some feel they are grieving for their children, describing education as burying their hopes.

A parent of a child with Down syndrome worries about the future and emphasised the importance of the right education. Another parent, currently engaged in the tribunal process to secure support for their child, described it as the most stressful experience of their life.

When discussing mental health, one child explained:

*"In my old school, there was a lack of accommodation around my needs, I was crying every day, I was stuck in this endless loop of going to school, getting bullied, coming home, crying, sleeping and doing it all again. My schoolwork struggled because I had to focus on constantly defending myself. But in my new school, it's a much more accommodating school and I have a lot more allies who now understand me. We even have some neurodivergent teachers. Having access to both ALN and well-being support has helped me massively. I tend to focus more on well-being and I go to their base twice every day."*

### **Lack of access to their rights:**

Some education professionals have not read the United Nations Convention on the Rights of Persons with Disabilities, leading to situations where people are still segregated, according to one parent. They attribute this to the overwhelming nature of their jobs and inefficient use of government funds.

Another parent, with a child with cerebral palsy, called for more integrated opportunities to avoid segregating disabled and neurotypical children. They advocate for more focus points for their child to integrate with neurotypical peers. Parents expressed frustration at being dismissed by people in the sector.

*"I know my rights but not everyone does and sometimes I contact professionals to get access to things and I am fobbed off, told to look at something else first and then come back if it's still a problem, they are putting up the barriers even when you say "I know I'm entitled to this.""*

Segregation of disabled children within education was described as "the norm." Families expressed concern that if disabled people were not visible in education settings, they would always be segregated.

*"If my son wasn't in a mainstream school, his non-disabled peers wouldn't know that he exists."*

*"School councils don't represent or capture minorities, or the voice of disabled children."*

The children generally felt listened to when in school, but "not all the time." For example, when the children wanted to take part in things they were not always told why that was not possible.

There is a financial impact on families due to having a disabled child:

*"Anything that's got "special needs" written in the title you can guarantee will cost more than anything else." – Parent of a child with Down syndrome*

Parents described how they often had to pay for things for their children due to their disability, this might be medical costs that would shorten waiting times, or every day equipment.

*"I've had to buy a number of cups / bottles as OT won't listen to me about what my son needs. I've also had to buy most things for the home including specialist bed / cups cutlery, adjustable table / desk .. wheelchairs (the one given is not fit for purpose and the NHS state Welsh Gov have said to only provide basic equipment). I provide extra nappies as I share mine with school. Welsh Gov don't cater for nappies ripping or the need for excess nappies if the child has a stomach bug - it's not easy and we have been on our knees with money issues but we do our best." – Parent of child with spinal bifida*

## Positives

While families generally report negative experiences accessing education and childcare for disabled or neurodivergent children, some positive comments were shared. Families express satisfaction when the child is in a positive learning environment, praising efforts to welcome and include them in the education setting.

*"I only ever had a good experience with the SEN school, they go above and beyond."*

*"I think the school has been excellent, they have changed things to help her. For example to help her visually, they have painted steps, changed the laminated signs to matt, they have really tried to help. If there were any issues, I feel like I could always pick up the phone and speak to them."*

This could be attributed to a number of staff within the workforce who are willing to ensure inclusion is a priority:

*"The secondary school experience was very positive in many ways. But the primary school experience was very different. Some individuals had a big effect on the attitude of the whole school."*

## 4. Solutions

During conversations, some suggested solutions were proposed by families:

- 1.** Enhanced teacher training is crucial;
- 2.** Collaboration between SEN schools and mainstream schools can improve communication skills among staff.
- 3.** Increased support and funding for external agencies benefit parents, providing a sense of community.
- 4.** Parents propose extending statutory leave for childcare (up to two weeks annually) for those with disabled children.
- 5.** Improved school communication, especially for nonverbal children, is essential.
- 6.** A centralised local authority coordinator could streamline support services for families.

7. All schools should integrate "quiet spaces" for universal accessibility.

## Annex 1 – Discussion Guide

Families were asked their views on the following questions:

- Can disabled and neurodivergent children and young people get everything they need in their school or nursery?
- Are disabled and neurodivergent children and young people left out of any part of their education?
- Have disabled and neurodivergent children and young people been unfairly treated?
- How is the mental health and wellbeing of disabled and neurodivergent children and young people? Do they do well at school or nursery?
- What things stop schools and nurseries from providing inclusive and accessible education? (Inclusive means everyone can take part, and everyone has a fair chance. Accessible means everyone can find and use something.)
- How well do schools or nurseries talk with disabled and neurodivergent children and young people and their families? Do they include them in decisions and choices?
- Do disabled and neurodivergent children and young people and their families feel they have the same choices as others?
- Are there services for different types of disability?

## Annex 2 – Stakeholder organisations

The Citizen Engagement Team approached and collaborated with the following organisations and charities to identify and support families to take part:

Both Parents Matter	The Hive and Carmarthenshire HELP Forum
British Association of Teachers of Deaf Children and Young People (BATOD)	TUC
Cardiff People First	Ty Hafan
Caring Dads	Valley Daffodils – Caerphilly based
Ceredigion Council	Valleys Kids
Contact	Wen Wales
CTM UHB - Community Health	
Disability Wales	
Epilepsy Action	
Faith in Families	
Flintshire County Council –	
Homestart	
Long Covid Kids	
MENCAP – Ynys Mon	
Merthyr Tydfil County Borough Council	
National Deaf Children's Society	
PAN (Parent Advocacy Network) West Glamorgan	
Parent and Carer network: YMCA, Bargoed	
Parents 4 Change	
Plant Dewi	
Sense Cymru	
STAND North Wales – Stronger Together for Additional Needs and Disabilities	
TGP	