

# SCOPE

= Equality for  
disabled people

## Our Lives, Our Journey

Disabled children  
and their families

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# Executive summary

We are proud to launch ‘Our lives, Our journey’. This study is the first known qualitative longitudinal study to follow the lives of disabled people and their families in the UK.

Disabled people and their families tell us that there are key moments of change in their lives which have a big impact on their experiences as a disabled person. We call these transition points.

At these points, the kind of support that’s available, the interventions that take place, and the decisions disabled people and their families take – or are taken for them – can make a significant impact on what happens next.

This study is designed to understand these transition points better. Too often we only see disabled people’s lives as a snapshot or single moment in time but disabled people’s lives change.

Becoming an adult, moving into work, growing up, adjusting to new health and support needs. These experiences are all part of a journey, a story of progress and setbacks, action and inaction that is rarely told in disability research. We aim, over five years, to tell this story.

This report tells the experience of 21 families with disabled children up to the age of five. In this study, their journey starts with the transition of their child either awaiting or being diagnosed with an impairment or condition. We explore each family’s experiences, both good and bad, and their personal aspirations for the future. We will be following how these disabled children and their families progress, sharing their experiences to understand how their lives change over the next five years.

The early years for any child is a crucial development stage that influences their opportunities to get the best start in life. Our research shows that life is harder than it needs to be for parents with a disabled child. Their time, resilience, finances, and choices available are all negatively affected. This is likely to impact on their child's development and deepen current inequalities.

The parents participating in the study reported on what had worked well for them and highlighted areas which enabled their disabled children to have a positive experience. Families showed resilience when encountering barriers imposed on their children by their communities and wider society. Parents tried to be proactive and find solutions to help support their children and themselves, such as applying for Disability Living Allowance (DLA) and Education, Health and Care Plans (EHCPs), or seeking formal and informal advice and support. Key areas highlighted were:

### **Diagnosis journey**

The diagnosis journey parents undergo for their child to be diagnosed for a condition and or an impairment is extremely challenging. During this time receiving an appropriate response and personalised support from the NHS was incredibly enabling for parents. This was particularly helpful when tackling the practical care issues of their disabled child, as well as providing support for parents with the emotional issues involved with their child's recent diagnosis.

Unfortunately, parents reported that the response and quality of support received during the diagnosis journey was very inconstant and largely dependent on the life stage at which their child was diagnosed. This level of support was commonly only reported for children diagnosed at birth or within the first year.

### **Support for parents**

Some parents proactively sought out support or advice from other families with disabled children and support organisations, mostly via social media or organised face-to-face events, such as forums, group meet ups or disabled children's play groups. A minority of parents also turned to counselling to improve their emotional resilience and well-being. Although the financial burden could be high, these sessions did provide parents with support through key transition points, helping them to accept their child's condition and assisted them in the development of coping strategies for raising a disabled child.

## **Benefits and supportive funding**

Parents were also positive about support they received from charities, local health professionals and other disabled people or families with previous experience of benefit applications. All parents found the benefit payments (such as Disability Living Allowance) and grants (such as Disabled Facilities Grant (DFG) or Family Fund grant schemes) extremely useful, once awarded – although applications were often more difficult than they needed to be. These funds were spent on the needs of their disabled children and family, and in addition to health needs, this included equipment, toys, and essential home adaptations, such as ground floor bedrooms, wet rooms, safety adaptations and lifts, all of which can be very costly.

## **Accessible options for families**

Families had positive experiences where places and services had been adapted to consider disabled children's accessibility needs, although availability of these options were limited, particularly playgrounds and soft play centres.

Where available, these inclusive and accessible approaches can make a huge difference to disabled people and their families. Parents highlighted good examples of accessible play facilities where available, such as:

- outdoor playgrounds or indoor play centres with wheelchair and disability friendly apparatus, such as wheelchair roundabouts or play areas with interactive sensory features, such as lights and walls
- sensory play facilities and areas that provide a quiet break
- adapted supermarket trolleys and autism packs to be used while shopping (for example, sensory toys and ear defenders)
- schemes to improve the experience and access of families with disabled children, such as fast track queues and supportive engagement with the family

## Nursery support

Overall, parents were pleased with the service and support received from nursery staff and facilities for their disabled children, and felt confident their children were getting the best start in life at nursery. They highlighted nurseries that were open, accessible, welcoming and designed for disabled children. They highlighted many examples of good practice, such as being flexible to cater for learning and disability support, or implementing adjustments for disabled children, like quiet areas and adaptations of play areas and apparatus.

## Support for starting school reception year

An effective Education Health and Care Plan (EHCP) was considered by all parents an important enabler for children to progress whilst at school. When an EHCP was not established or not prepared effectively, it could result in serious issues for disabled children and significant stress for parents. Delays and poor support from local authorities and EHCP panels often led to plans not being put in place in good time for children starting school. A few parents reported their choice of school for the child was adversely affected by this.

Parents highlighted, where nurseries led the EHCP, the experience of the journey to establish the plan was significantly better and there was usually a smooth transition into schooling. There was good coordination and input from different professionals to create an appropriate and timely plan for the disabled child.

Unfortunately, these positive experiences were not common place for disabled children and their families. Despite the diagnosis of a child's impairment or condition being a life changing event that is extremely emotional and challenging, many parents reported there is a lack of statutory support, advice and practical care for their disabled child, as well as emotional support for themselves. Furthermore, parents frequently highlighted barriers for them and their disabled children within their local communities and wider society.



Through following our participants experiences, families with young disabled children faced a range of issues:

**Inconsistent diagnosis support:** Parents went through varied and complex diagnosis journeys and needed support and advice for their children and themselves. Unfortunately, parents reported that there is inconsistent support from the NHS or local authorities. The level of statutory support they received often varied based on the timing of the diagnosis, with family support needs often not available or inadequate.

**Care and support:** Parenting a disabled child can lead to extra care responsibilities beyond that required for a non-disabled child. This adds to the challenge of parenting, reducing personal time and respite opportunities, sometimes leading to an increased experience of loneliness and social isolation.

**Emotional support:** The extra care responsibilities and period of transition can place pressure on parents' emotional resilience. Family and friends, therapy sessions, and other parents who have had similar experiences can be key sources of support. However, there is typically an unmet need faced by parents, as these types of support are informal, require self-funding, or are difficult to sustain due to time constraints.

**Noninclusive environments:** Families are consistently faced with poor experiences of access to everyday leisure activities and public places – inaccessible design, lack of flexibility and adjustments, and negative attitudes and behaviours of staff and other parents and users where frequently raised. These poor experiences negatively affect parents and their children, creating barriers to certain places and engagement with the community.

**Limitation of choice:** Early in their child's life, restrictions of accessible options lead parents to choose disability-friendly places to search out positive experiences, whether that be the choice of school or leisure activities. However, this limitation of choice is likely to reinforce exclusion from experiences with non-disabled children, which reduces disabled children's socialising opportunities, choice of activities, and developmental opportunities.

**Financial pressure:** Parents face a variety of extra costs in raising a disabled child: extra consumption (such as travel needed due to medical appointments); specialist equipment (such as sensory toys); and paying for services due to a lack of suitable provision (such as therapies). Disability Living Allowance (DLA) can be a key source of support but the application process is complicated and can cause significant anxiety.

**Educational needs:** Education Health and Care Plans (EHCPs) are a key support document for providing integrated support in school, enabling parents to choose appropriate support for their child. However, as with DLA, our families told us the application process felt too long and emotionally challenging, with a lack of support from local authorities. This forced parents to undertake research themselves and rely on external support.

More broadly, parents also talked about the lack of, and need for, improved levels of awareness and understanding of disability in society. They felt this restricted engagement in the needs of their child, leading to a lack of support and higher levels of exclusion in society.

Improving awareness and understanding of disability would alleviate problems faced in other areas, such as in the design of support, application processes, products and services.

When thinking about the future, parents identified their key aspirations for their children as, finding a suitable school and their child progressing, making friends and building relationships. These are similar aspirations to parents with non-disabled children. But achievement of these could be of greater concern given their past experiences. We hope these aspirations are achieved, and we look forward to seeing if they occur in future years of the study.

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# Introduction

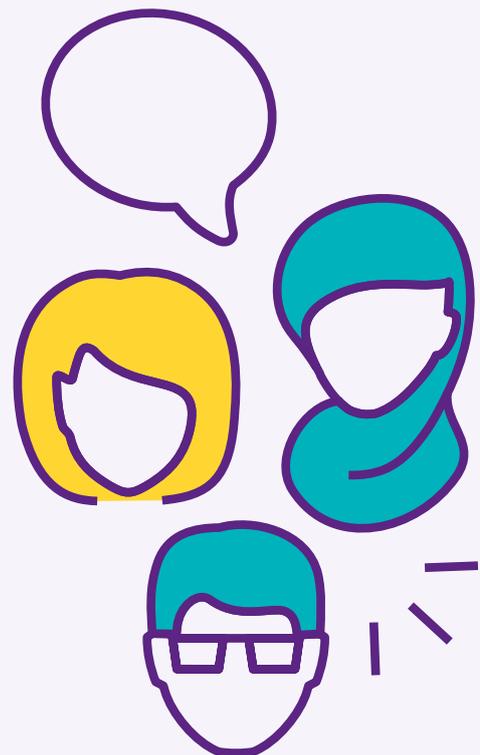
Sponsored by the Esmée Fairbairn Foundation, 'Our Lives, Our Journey' is a pioneering longitudinal qualitative research study, following the lives of disabled people over five years. The research aims to provide a rich qualitative evidence base into the life journeys of disabled people. It will focus on key transition points in disabled people's lives and explore what prevents or supports them and their families to live the life they choose.

The study focuses on four specific groups of disabled people:

- parents of disabled children
- young disabled people (aged 16 to 21)
- disabled people with a recently acquired impairment
- disabled people recently gaining employment

Data was gathered through in-depth semi-structured interviews with each participant. We discussed their life journey, their aspirations, and their experiences of disability and everyday equality. We looked in detail at how they negotiated key transition points in their lives (for further details of the methodology and sampling used please see the appendix).

The interviews from year one of the study were thematically analysed and the main themes across all participants were aligned and explored in detail. In particular, common barriers for parents and their disabled children, as well as useful and positive solutions.



# Our participants

**Rebecca** is Mum to one-year-old **Olivia** who has a physical impairment.

**Jane** is Mum to three-year-old **Katryn** who has physical and vision impairments.

**John** is Dad to five-year-old **James** who has learning and physical impairments.

**Toni** is Mum to four-year-old **Daisy** who has learning and physical impairments and an autism spectrum condition.

**Rhian** is Mum to four-year-old **Menna** who has learning and physical impairments.

**Charlotte** is Mum to two-year-old **Felicity** who has hearing and vision impairments.

**David** is Dad to two-year-old **Alice** who has physical and vision impairments.

**Charlotte** is Mum to five-year-old **Raphael** and **Theodore** who have learning, physical and vision impairments.

**Helen** is Mum to five-year-old **Jack** who has autism.

**Natalie** is Mum to four-year-old **Harry** who has learning and hearing impairments.

**Susan** is Mum to four-year-old **Nathan** who has learning and physical impairments and an autism spectrum condition.

**Sarah** is Mum to two-year-old **James** who has a physical impairment.

**Jools** is Mum to four-year-old **Zara** who has a learning impairment.

**Vicki** is Mum to four-year-old **Daniel** who has a physical impairment and autism, and three-year-old **Phoebe** who has a vision impairment.

**Andrea** is Mum to four-year-old **Emma** who has learning and physical impairments.

**Kay** is Mum to four-year-old **Zarah** who has autism.

**Rebekah** is Mum to four-year-old **Sebby** who has learning and hearing impairments.

**Richard** and **Cheryl** are Dad and Mum to three-year-old **Alexander** who has learning and physical impairments.

**Donna** is Mum to four-year-old **Alfie** who has a physical impairment and autism.

**Christie** is Mum to three-year-old **Elsie** who has a physical impairment.

**Shell** is Mum to four-year-old **Oliver** who has autism.

# 1. Diagnosis journey

The diagnosis of a child's impairment or condition is a life changing event. For the parents we spoke to, this transition point has been extremely emotional and challenging. Beyond medical needs, parents required support and advice on practical care for their child and emotional support for themselves. Currently there is inconsistent provision for both, and at times there is no support available.

Our analysis finds four common diagnosis experiences. These diagnosis types are determined by the timing of the diagnosis, which affects the quality of parents' experience of receiving advice and support.

## Diagnosis life stage typology



1. Moving towards a diagnosis during pregnancy



2. Diagnosis at birth or within first year



3. Early years diagnosis (aged one to five years old)



4. Ongoing diagnosis (tests ongoing and/or condition still emerging)



## 1. Towards a diagnosis during pregnancy

Some parents were informed that their child could be born disabled. For example, following the detection of developmental conditions, like spina bifida or Down's syndrome. Diagnosis at this stage can be extremely challenging. Parents may need to decide whether to undergo additional tests, which may cause risks to the unborn child. A potential diagnosis has led some parents to undertake intensive research in these areas.

In some cases, parents were given the option to terminate their unborn baby. Several parents felt that the health system was geared towards pushing termination and reported that this option was presented consistently throughout the pregnancy, as experienced by Richard and Cheryl during Alexander's diagnosis journey:

**"... I was probably told about seven times in various appointments in the 16 weeks before he was born, 'You don't have to go through with this, you know' or 'there are other options.' I was 36 weeks at that point... I do remember the specialist nurse going out after the appointment with us and sitting in the waiting room because I was just so upset that this doctor had suggested that, you know, we terminate at that stage, and then, two weeks later, he was born. Yes, at the time, it was very difficult to get your head around. Very emotionally distressing..."**

Richard and Cheryl, Dad and Mum to Alexander (aged three)

Parents also raised concerns that they had only been offered NHS counselling if they chose to have an abortion, and not if they continued with the pregnancy. Parents identified a lack of 'impartial' counselling support. If provided, such support would help prepare parents emotionally for the birth of their child, at a stage that can be extremely challenging.

Parents reported making links with other parents, both face-to-face and online, who had been through similar experiences. Talking with people who had shared similar experiences enabled parents to consider what life could be like in the early years of a disabled child's life, as well as providing them with positive aspirations about the future.

## 2. Birth and first year diagnosis

Parents with this diagnosis type reported receiving good NHS care and support. Where a diagnosed condition had required post-birth surgery, parents were grateful for the care they and their child had received. They appreciated help with practical issues, such as baby feeding challenges.

Furthermore, NHS staff were mainly empathetic when informing parents of their child's diagnosis. Parents also found themselves faced with new challenges, such as how to cope with potential hospital visits and any subsequent surgical procedures.





### 3. Early years diagnosis (aged one to five years old)

Children with this diagnosis type were diagnosed when the child was a little older. Diagnoses included conditions and impairments that were not or cannot be identified initially. This includes physical conditions and autism or learning disabilities.

Upon diagnosis, some parents reported the support was lacking, and were only given a booklet by medical staff on their child's condition. Parents also reported that there had been no short term follow up. Many parents expressed concern in securing further support, especially around their child's ongoing care and practical choices (such as in choosing and starting school):

**“We were given a book to take away... I didn't find the book particularly helpful... I think especially once you first get the diagnosis like we got... I think the local authority need to be better prepared and more geared up to make support available at point of diagnosis.”**

Shell, Mum to Oliver (aged four)



### 4. Ongoing diagnosis

There were some children who had emerging symptoms so their diagnosis was delayed or tests were ongoing. Children had symptoms such as developing mental health issues or a rare physical condition. Parents reported uncertainty about not having a diagnosis, and were concerned about their child's new and emerging symptoms.

The need for support didn't stop at diagnosis. Parents often required ongoing practical support for their child, and their own emotional wellbeing. Again, these needs were not consistently met, often increasing the strain placed on parents' emotional resilience.

# 2.

## Ongoing support needs

## Care support needs for children

Supporting a disabled child often means extra care responsibilities. These are frequently provided by parents, by key family members, or via privately funded care. Parents highlighted that the most common extra child care activities were associated with sleeping and restlessness through the night, eating, dressing and monitoring the safety of their child.

Many parents reported that they experienced fatigue supporting their disabled child. Richard and Cheryl reflected this:

**“I think it’s quite mentally exhausting as a parent, just knowing that you just have to, all the time, be alert. You’re on this heightened state of alert all the time.”**

Richard and Cheryl, Dad and Mum of Alexander (aged three)



## Emotional support needs for parents

Fatigue caused by providing extra care, as well as a lack of personal time led to significant challenges and increased pressure on parents' emotional resilience.

Counselling was seen as a solution by parents, but there were problems with long waiting times, limitations on the number of available sessions, and a difficulty in qualifying for NHS provision. One mum commented:

**“... unless you're suicidal or self-harming you don't meet their criteria. So it has been quite difficult for us to find a place as a family where we're going to fit. So we haven't had any kind of informal or formal support but I see a (private) counsellor...”**

Jools, Mum to Zara (aged four)

To obtain the counselling support they needed, a minority of parents reported employing regular private counsellors, bearing these extra costs themselves. This either took the form of one-to-one sessions or group counselling with family members.

Those who had proactively taken up counselling found it valuable for:

- support through this transition point
- help with acceptance of their child's condition
- venting frustrations and building coping strategies

**“[The counselling] allows me to be emotionally level enough to then fight those battles out with the services. It helps me moderate myself and work on the depression I experience because I've already done my angry thing in counselling. So, I've found it a really good coping strategy, but I have to pay for it...”**

Helen, Mum to Jack (aged five)

As couples, parents felt that they could only support each other so much and didn't feel equipped to provide the support required as with individuals experiencing different emotions and a range of motivations:

**“With family and friends, I think it’s just completely changed. Even between Mark and I, I think the emotional support that we need is quite different to what we’ve ever experienced. Usually, I would turn to Mark for my support, but he can only do so much because he needs the support...”**

Rebecca, Mum to Olivia (aged one)

Parents differed in their access to family support networks, with some having family close by, while others were more isolated.

When asked about different types of support, many parents expressed an interest in seeking counselling for emotional support. Parents also wanted to share and discuss issues with other parents of disabled children. Areas they welcomed support and advice with, were issues such as:

- parental stress and anxiety
- sleep deprivation issues and effective sleep management when their child wakes during the night
- feelings of loneliness associated with looking after a disabled child
- family relationship pressures parents and other family members share

**“I think you become very vulnerable initially and your emotions are all over the place. But then you have to become quite strong, as a parent, and it would be good to understand that. Maybe have some type of counselling available that allows people to get their emotions out in that vulnerable period where they’re not sure how to feel. Just understanding that there are a lot of emotions that will be going on along that time.”**

Kay, Mum to Zarah (aged four)

## Support from friends and other parents

Some of the parents' friendship groups had changed since their disabled children were born. Parents reported that although one or two close friends continue to be supportive, other friends have dropped away. Some parents believed that people they had longstanding friendships with were deliberately staying away, and that these fading friends had difficulties adapting. In addition, some parents found it difficult to travel, so friends needed to make the effort to visit them to maintain close contact.

Other parents of disabled children were regarded as key enablers through sharing life journey experiences and by providing emotional support and practical advice. Parents made connections with other parents by joining disability groups through social media platforms such as Facebook and Twitter. Some parents also formed or joined local groups to bring families together. Rebekah mentioned her husband was part of a group for fathers of children with Down's syndrome:

**“They have a dad’s group... they try and meet monthly... Mike said that when he went the first time, that it was the first time since Sebby was born that he’d actually spoken to anybody, or another dad, about having a child with Down’s syndrome, and he finds it really reassuring to go and really supportive.”**

Rebekah, Mum to Sebby (aged four)

Parents highlighted the importance of social media groups for emotional support:

**“I found a lot of help in social media. So, I just chat away on Twitter. You find parents in similar situations... and you’re talking to each other as if you’re best friends. I’ve actually found that a massive emotional support. That’s my turning point now – where I’ll rather go online and talk to a parent that’s going through a similar thing and they, again, can turn to me and go through their emotions.”**

Rebecca, Mum to Olivia (aged one)

Some parents used services or attended events to meet other disabled families. These included condition-specific conferences, services and events run by disabled children’s charities. Parents considered disabled children’s charities as good enablers for all the family. Charities supporting and providing facilities for their children’s play time were found to be particularly helpful for the disabled children and their family.

Where parents had other children in their early to mid-teens, teenage siblings had also attended young carer charity events. Parents reported that young carer charities helped these young people to share experiences of caring and supporting their disabled siblings or family members.



# 3.

## Public places, attitudes and behaviours

Public places are important for all children and their parents. It is where families interact with other families and play a central role in children's development, social connections and their happiness and wellbeing. They range from playgrounds and parks, to supermarkets. However, when visiting these places, parents reported inconsistencies in their accessibility. This made disabled families feel they weren't being treated equally, and that they were being excluded from certain areas of society.

## Inaccessible by design

The design of places and services affects how easy they are to use. Parents frequently reported situations in which the needs of disabled children had not been considered, which either made them inaccessible or created a poor experience for disabled children.

For example, several parents commented that some places they visited had inaccessible pathways and routes, in addition to challenging terrain, including uneven floors and tight spaces. This presented barriers when pushing wheelchairs or adapted children's buggies. It was also mentioned that outdoor playgrounds can often have harsh or unhygienic surfaces for disabled children, such as bark or the presence of litter, which was a particular issue given that some disabled children crawled more than others.



Some leisure services could not be used because the facilities were badly designed. Inaccessible toilets and changing spaces presented a barrier, especially when they were fundamental to the activity, such as in swimming pools. Parents commented that they had to go to private swimming pools in order to access larger, more appropriate changing facilities. They also highlighted that accessible specialist pool facilities in Special Educational Needs (SEN) colleges would very likely improve swimming experiences and lessons in the future:

**“Nobody should have to change their child on a toilet floor. It’s disgusting. ... So quite often you’ve got to wait a very, very long time for the one disabled toilet that you really need to get in. Maybe they need to put more toilets in.”**

Vicki, Mum to Daniel and Phoebe (aged four and three)

Parents also reported that rules, which govern how spaces operate, are not flexible enough to be relevant for their child’s needs. For instance, some soft play centres impose rules that you cannot help children on the equipment, even though some parents felt their child needed assistance:

**“Soft play, it was just so negative, the guy was very strict in as much as, ‘No adults are allowed on this soft play equipment’... That was really rubbish, and was of no interest because all of his mates were over there on that big slide, but he couldn’t do that.”**

Donna, Mum to Alfie (aged four)

## Availability of accessible services and equipment

Families had positive experiences where places and services have been adapted to consider disabled children's accessibility needs.

**Some parents did highlight good examples of accessible play facilities, such as:**

- outdoor playgrounds or indoor play centres with wheelchair and disability friendly apparatus, such as wheelchair roundabouts or play areas with interactive sensory features, such as lights and walls
- sensory play facilities and areas that provide a quiet break
- adapted supermarket trolleys and autism packs to be used while shopping (for example, sensory toys and ear defenders)
- schemes to improve the experience and access of families with disabled children, such as fast track queues and supportive engagement with the family

These inclusive and accessible approaches can make a huge difference to disabled children and their families, as exemplified by Rhian's experience of Peppa Pig World, an attraction praised by all participants who attended:

**“Last year, we went to Peppa Pig World for Menna's birthday... the facilities for disabled children and adults. It was brilliant. I'd never seen anything in a public place like that... you can push the wheelchair straight on.”**

**Rhian, Mum to Menna (aged four)**

Accessibility was a key consideration for parents when choosing leisure activities. As a result parents tended to visit accessible places more frequently. Meeting other families of disabled children, and the subsequent increase in frequency of use, helped to reinforce these accessible places as good services or facilities to use (with the presence of other disabled children providing a positive signal). While this was a positive and accessible experience, it also led to reduced contact with families of non-disabled children. This also reduced opportunities for disabled children to spend time with their non-disabled peers.

Regrettably, parents reported that this type of provision was rare and inconsistently available. Families experienced frequent issues with inaccessible play facilities or leisure spaces and inappropriate service delivery by under-trained staff, which effected their children's equality and ability to play.

For instance, some parents commented that soft play centre equipment was too big or too small for their child. This led to some small, early years disabled children being held back in the baby and toddler area, rather than playing with their age peer group, which was frustrating for the child and their family.

Furthermore, many parents reported that some soft play centres impose rules that restrict or even prohibit helping children of a certain age on the play equipment. It was felt that staff imposing the rules often lacked empathy or awareness of disability. Parents and siblings that were told to exit the play area were particularly upset by this.

Accessible soft play centres have disability friendly apparatus on offer, such as sensory walls and lighting. They are also wheelchair welcoming and have empathetic, disability aware staff. Unfortunately parents found these types of centres to be in a minority.

## Attitudes and behaviour

Other people's attitudes and behaviour can also play a key role in facilitating a negative or positive experience. Parents commonly said that attitudes and behaviours were based on an individual's understanding and awareness. Positive experiences were associated with people who were empathetic and demonstrated welcoming behaviour. Negative experiences were associated with rigid, uninformed or inconsiderate behaviour.

Based on this experience, participants felt that understanding and awareness of disability needed to improve to enable equality in society. Their experiences showed them that this lack of awareness was holding people back from being supportive and understanding. Participants felt services and schools should deliver disability awareness education alongside learning about visible and non-visible conditions. This could break the cycle of a persistent lack of understanding. As the attitudes of tomorrow's parents will be shaped by how disabled children are treated today, parents felt disability awareness education was crucial to allow families to be equally included in society:

**“If you build awareness from a young age, then you're not going to have the attitudes that you have. You're going to have understanding and that's all, really, disabled people want. An understanding and awareness so they can be treated the same.”**

John, Dad to James (aged five)

## Public attitudes

Participants recalled receiving mainly negative attitudes from the public. Experiences ranged from their children getting tuts and being stared at, to being approached by members of the public telling them to ‘shut up your naughty children’. These attitudes and behaviours were felt to be ignorant, judgmental and were obviously very hurtful.

Parents mentioned that, historically, there has been a lack of disability education in schools and wider society, which they felt has led to a degree of pity and ignorance towards disabled people that needed to change. This was the result of unwelcoming opinions and questions, highlighted by participants in such examples as:

- ‘You are brave’
- ‘I’m the world disability expert – here is my stereotypical opinion’
- ‘Will she be cured?’
- ‘Why is he funny looking?’

Some parents also reported members of the public judging them by incorrect assumptions and telling them off for parking in Blue Badge accessible parking spaces. These incidents tend to happen in supermarket and shopping centre car parks and can be very confrontational:

**“With people’s attitudes, I think that just goes down to people not having awareness really - or the understanding or not wanting to understand. Until you have a child with an additional need you don’t actually realise how naive you are about it, you don’t realise how - because unless you need to know, you don’t know.”**

Andrea, Mum to Emma (aged four)



## Staff attitudes

Participants reported receiving an equal mix of positive and negative attitudes from service providers' staff. Staff with good attitudes are welcoming and open to learn more about disabled children's accessibility requirements, they were happy to adapt their behaviour and support disabled children to enjoy activities. Staff that were helpful and facilitated a positive experience were happy to adapt their behaviour and support disabled children to enjoy activities:

**“A lot of the zookeepers will be a lot more patient with him when they're doing animal experiences. If you say, 'He's not good with crowds, but we want to have the touchy feely experience,' they say 'Well, we finish at 3pm for this experience. Come back at ten past, and when it's quiet, we'll get whatever animal it is out.' He usually likes the reptiles, so he'll go and pet the snakes, or pet the iguana. I couldn't praise Colchester Zoo highly enough.”**

Helen, Mum to Jack (aged five)

Negative examples showed converse scenarios, with staff rigidly applying rules or being rude:

**“I actually put in a formal complaint about a member of staff, because my son was having a meltdown in the middle of the tinned goods aisle. I'd told him he wasn't allowed to pull them off the shelves, so he had a meltdown, and I overheard a member of staff call my kid a spastic! I was not impressed in the slightest... I went, 'Did I just hear you correctly? Did I just hear you call my kid a spastic?' He just goes, 'Well, if the boot fits...’”**

Helen, Mum to Jack (aged five)

## Families with non-disabled children

Parents recalled receiving mainly negative attitudes from parents of non-disabled children. This was a source of frustration as they were keen for their child to integrate with non-disabled children, so that their child had the same friendship and development opportunities as others. Our parents wanted other children to understand more about disability, but they felt this was not currently possible. The three most common attitudes and behaviours experienced were:

### 1. Lack of engagement or ignoring

In some cases, parents were unable to make friends at new baby groups. They experienced parents of non-disabled children were not engaging, ignoring them and their child, or excluding them from social events:

**“Well the first time it happened he was only six weeks old and we went to John Lewis and we were in the cafe and a woman moved tables. She moved tables and she said to her daughter ‘look at that baby do you think they’ve dropped him on his head’... Oh, you’re going to make me cry!..”**

Vicki, Mum to Daniel and Phoebe (aged four and three)



## 2. Restricting their child's interaction

Parents used positive terms to describe other children's interactions with their children, such as 'caring', 'helpful', 'learning' and 'inquisitive.' Shell highlighted this positive interaction by praising her son's friend:

**“There's a little girl called Hannah in his mainstream nursery. She knows he's a little bit different, and she realises. She's old beyond her years, and she keeps saying to me, like, before Oliver was talking, she was like, 'We have to talk to Oliver lots, so that he learns how to talk.' She tries to help him, and she's really quite fond of him and helps him along.”**

Shell, Mum to Oliver (aged four)

Unfortunately this inquisitive interaction can often be stopped or limited by the parent 'shushing and ushering' their child to avoid interaction. This can be disheartening for parents who want their child to engage in conversation.

## 3. Patronising and invasive attitudes

Some parents report being asked invasive questions and receiving patronising sympathy, such as those mentioned in the general attitudes section.



# 4.

## Financial security

## Disability Living Allowance journey experience

Disability living allowance is a benefit which can help with some of the extra costs faced by families raising disabled children. Overall, feedback from parents was largely negative about the Disability Living Allowance (DLA) application journey with the Department of Work and Pensions (DWP) (please see Appendix C for details of the DLA key journey stages).

The form is long (currently 62 pages), difficult to complete and a cause of significant anxiety. Parents reported that the form contained confusing terms which were challenging to understand, and duplicated information already submitted in other applications. Parents felt like they were being asked to be overly negative about their child and this made the form upsetting to complete.

Whilst parents welcomed DLA and acknowledged its importance, they were generally negative about the application process and the confusing questions on the form. For instance, questions about quantifying the time it takes to do activities. Parents highlighted these needed to be more specific to the age and type of disability.

For example, the question, ‘Would your child talk to a stranger?’ left parents confused:

**“Would he talk to a stranger? Would he not talk to a stranger? You know, if we were lost in Asda, because of Alfie’s speech delay, if you found him and you asked him something, you might not be able to understand him anyway... I kept finding myself writing, ‘Because of Alfie’s speech delay, you wouldn’t be able to understand him, unless you know him and you know what he was telling you about?’”**

Donna, Mum to Alfie (aged four)

Or parents found they were often asked to answer an ambiguous question:

**“How long does it take your child to get out of bed? Is that physically? Is that behaviourally? The way the questions are worded, it’s not clear. They’re not focused. They’re very, very vague.”**

Charlotte, Mum to Felicity (aged two)

Parents valued support to complete the DLA form. This came from a variety of sources including charities, nurseries and health professionals. Parents felt the best advice was tailored, and from people with direct experience of applying for DLA themselves:

**“Actually, when you talk to a nurse about it, they go, ‘Yes, parents play with their child,’ but on this form, what you need to say is your idea of playing with your child is doing physio for three or four hours a day with her, that also happens to be play... So, the advice was good.”**

Jane, Mum to Katryn (aged three)

A few parents were declined DLA payments. These decisions, which were felt to be wrong by the parents, were hard to cope with and challenged their resilience. Experiences like this, left parents frustrated:

**“We got the statement of reasons. It said that they felt that having a catheter was no different to changing a nappy. So, it wasn’t significantly different to a child of Felicity’s age.”**

**“Angry. Like these people, clearly don’t know anything about the medical needs. It, sort of, bamboozles me that the people who make these decisions aren’t, in anyway, medically trained.”**

Charlotte, Mum to Felicity (aged two)

Happily, all these parents went through the mandatory reconsideration and appeal stages and had their decisions overturned. This led to the impression that DWP rejects decision in the hope applicants may not appeal them. This creates a trust issue for future reviews, and also means that some parents who are less persistent or resilient may just accept the decision and miss out on DLA.

In addition, when parents were challenged with the result of their DLA application, they went through a mandatory reconsideration or appeal process. Although all parents were eventually awarded DLA, decisions were reversed just before tribunal hearings, causing unnecessary stress and financial strain on the family. Parents were upset when they found out the reasons the DWP had rejected their application and felt that there was often a lack of understanding of their child's disability:

**“I cried. Mark got home to just a blubbing wife on the sofa. It was destroying because it felt like a slap in the face because everybody's saying that your child's ill, everybody's saying that she needs the extra help, that she needs this, that and the other. Then this brown envelope just says, 'No, she's fine.' It was just soul destroying.”**

Rebecca, Mum to Olivia (aged one)

Throughout this time, parents were positive about support received from charities, local health professionals and other disabled people or families with previous experience of the DLA application process. All parents found the DLA payments extremely useful once awarded and it was spent on the needs of the child and family.

## Extra costs for families

Families with disabled children face extra costs to achieve the same standard of living as an equivalent family with non-disabled children. Parents highlighted the frequent circumstances and key activities or areas of extra costs for their family when raising and supporting a disabled child:

- Buying more every day products and services (for example bedding, footwear, travel to hospital).
- Buying specialist disability products or services where prices can be often higher (for example sensory toys or support suits).
- Paying for an unmet need due to a lack of suitable provision (for example therapies).
- Paying higher prices for non-specialist goods or services (for example travel insurance).



## Specific example of disability-related extra costs

The most frequent extra costs experienced by parents are: transport, toys, clothes, energy, therapies, and home adaptations, with areas of extra costs for families detailed below.

### Transport

Parents highlighted the impact of costs associated with car travel to hospital and car parking charges, extenuated by frequent hospital visits for outpatient appointments and inpatient stays.

Jools' example emphasised the feedback from parents:

**“Well Zara’s appointments are at least an hour and our local hospital’s 20 miles away. So, each trip is expensive. So that would be our big disability related cost.”**

Jools, Mum to Zara (aged four)

In addition, some parents had to invest in a second car to attend these essential trips, particularly when partners had to work. Parents also reported that they had to buy larger, adapted cars that could transport wheelchairs and adapted buggies, which were more expensive. They also often had to buy specialist, extra supportive and higher-priced car seats for their disabled child. Families tended to travel further to access disability friendly activities, such as driving a longer distance to the nearest disabled children’s play centre.





## Toys

Families liked to buy sensory toys to enable enhanced play and stimulation for disabled children and improve physical ability and learning. The toys had features such as sensory lights and vibration settings. Parents highlighted the expense of these products and shared their frustration at the high price tag of disability. Some parents found ways to reduce these costs by accessing toys via:

- local toy lending libraries (public and charity operated)
- Family Fund grants for sensory toys
- other parents of disabled children online – signposting and advice based on experience and child use

Sarah highlighted some of the issues experienced by parents:

**“That’s one of these special-needs toys. Some of these that Portage<sup>1</sup> loan us, and the Bradford Toy Library loan us, we bought this one for James, because he really likes it. I’m on a special needs buy and sell site and I paid £40 for it. It would have been £70 new. People are selling them, obviously just over half-price, if they’re in good condition.”**

Sarah, Mum to James (aged two)

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<sup>2</sup> Portage is a home-visiting educational service for pre-school children with SEND and their families.

### **Clothes**

Some participants bought specialist children's clothing to ensure that they fitted well, as well as providing the comfort and extra physical support needed. These are often more expensive than supermarket alternatives, and can lead to parents importing products. Some parents also spent more on nappies, due to their children wearing them to a later age.

### **Energy**

Some parents reported higher levels of heating use, to protect their children, as some disabled children are more sensitive or susceptible to the cold. Parents also mentioned higher energy use due to the need to regularly wash bedding and clothes following accidents, or using energy-intensive therapies equipment, such as a hot tub for hydrotherapy.



## Therapies

Several parents paid for private therapies for their children or themselves. This included physiotherapy, hydrotherapy, personal swimming lessons, speech and language therapy, applied behaviour analysis (ABA) and parent counselling.

Parents found that regular ongoing therapies on the NHS were very limited, tending to be in blocks of six sessions. Waiting lists were frequently too long and there were inconsistent options available, often dependant on location. This situation did not meet parents' aspirations for their children. As a result, several parents chose to pay for private therapy services. Although they were pleased with the quality of support received by private therapists, parents had to pay higher fees than were covered by their family benefit payments.

Helen commented on this situation:

**“I pay probably about £600 a month in therapies for my son... I do that privately, because at the moment, the services are in such a shambles... From doing the therapies and doing right by your child, you're immediately on the back foot. You're now worse off. So, you now have to work harder to bring yourself back up to that level, but the perception of people is, you get given a lot of money by the government, so you shouldn't be struggling...”**

Helen, Mum to Jack (aged five)

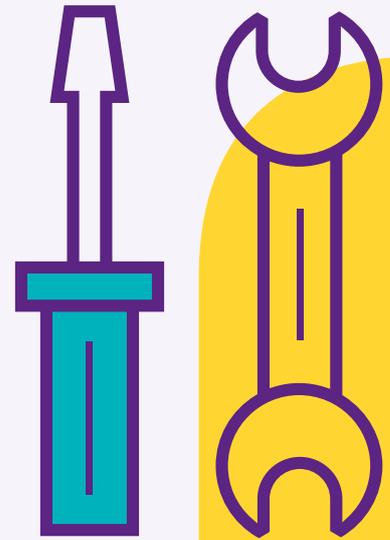
### Home adaptations

A few participants have made home adaptations, such as ground floor bedrooms, wet rooms, safety adaptations and lifts, all of which can be very costly. The Disabled Facilities Grant (DFG) scheme helped some parents with these costs, and other parents had applications in the pipeline. The grant is an important factor in enabling families to meet their household costs.

Jane describes the contribution the DFG has made to her home adaptations for her daughter Katryn:

**“What we had to do for Katryn was to do a bedroom and wet room bathroom next to each other, so that a hoist can go across... We’ve also... built like a living area or playroom area... We’ve put bifold doors on each side of that, with a patio, so that Katryn can get out. One’s a ramped patio.”**

Jane, Mum to Katryn (aged three)



# 5.

## Nursery and school support

## Education, Health and Care Plan (EHCP) support

The EHCP aims to integrate support for disabled children's health, social care and education needs. Parents see it as a key enabler of equality for their child, however they told us the EHCP application journey was frequently inconsistent and a major cause of frustration and worry (Appendix B shows this at each stage of the process).

Apart from being an extremely lengthy process (sometimes taking 18 months to complete), when applying through their local authority, support for parents was often cited as very poor and caused considerable problems in establishing an appropriate EHCP for the disabled child. Allocation of caseworker resource was often felt to be slow and understaffed. This can delay planning beyond the time when non-disabled children's school places are confirmed, so parents of disabled children wait longer to have their school place confirmed. There is typically little guidance offered and decisions were usually left to the last minute. Parents experienced unnecessary anxiety at a critical time, described by some as a 'battle'.

Susan outlined the lack of support she and her husband received:

**“There weren't people telling us the process... We were left in the air sometimes, not knowing what was going on... you'll soon have a caseworker who'll phone you and come for a visit. Nobody came for a home visit to see us. We didn't have a caseworker for many weeks after that...”**

Susan, Mum to Nathan (aged four)

Some parents had to appeal decisions made by the local authority to change the plan. Parents faced complex legal hurdles and the burden of researching their rights, as little or no information was provided by the local authority.

Jools described her experience of receiving a negative decision:

**“...when you get to the point that it’s been declined suddenly, like I had to go and read legislation and research all around the different areas and look at the process of what you have to do. To go through appeals is not very easy. It’s not very well explained.”**

**Jools, Mum to Zara (aged four)**

Conversely, where nurseries led the EHCP application, there was usually a smooth transition into schooling. There was good coordination and input from different professionals to create an appropriate and timely plan for the disabled child.

When plans are consulted on and agreed, EHCPs are viewed by parents as key to getting the support they need. Plans need to be implemented and refreshed on a regular basis. Some participants reported issues with integrated support provision for their children just starting reception year. For example, speech and language professionals didn’t attend school from the start to support children.

Although feedback about their first year of school was good, there were two common negative issues with the support received since the children had started school:

- **Therapeutic support** – Therapy required in the EHCP had not yet been provided (such as speech and language therapy), with many parents reporting that waiting times for appointments were causing problems. Parent confidence could be better built from the very start of school reception year by more timely appointments with professionals.
- **Progress reports** – EHCP communication report books sometimes contained very generic feedback. Parents needed more specific information as they regarded the communication report book as an important feedback and ‘lifeline’ to understanding the progress of their child at school.

## Nursery support

Although negative reports about nurseries were rare, a few parents reported changing nurseries where their children had not been appropriately cared for. These nurseries were not willing to take on disability training and posed barriers for children to progress. A few parents reported nursery staff ignoring inappropriate behaviours of other nursery children and that their child was ignored and left in a corner or the 'baby area'.

Overall, parents were complimentary of nursery staff and nursery facilities for their disabled children. Parents felt confident their children were getting the best start in life at nursery. They highlighted that those nurseries that were open, accessible, welcoming and designed for disabled children demonstrated many examples of good practice, such as being flexible so learning and disability support could be catered for. They also reported that many nurseries have implemented adjustments for disabled children, like quiet areas, sensory toys, and adaptations of play areas and apparatus:

**“They took the OT’s [occupational therapist’s] advice and adapted the whole playing area for James. It looks totally different now he’s not there but that’s what they were willing to do, so that’s fantastic.”**

John, Dad to James (aged five)

A key consideration and concern of parents was the application of nursery and school placements for their disabled children. Some parents mentioned that some nurseries were cagey and disinterested in accommodating disabled children, which restricted choices. With limited support this put further pressure on parents:

**“I walked into nursery one day and she was sat on the mat playing with her toys without help. That was a huge achievement for her, and I won’t ever forget the feeling of pride I had for her.”**

Christie, Mum to Elsie (aged three)

## School reception year support

Most of the school age disabled children were attending their reception year at school. Overall, parents reported that their children were integrating well and enjoying school. Many parents felt that their children were accepted and that they were achieving equality of opportunity. Some schools were complimented for the one-to-one support they provided, enabling the children to build independence. This was in addition to different learning support methods which helped the children progress. This approach had a positive influence on staff and parents, as highlighted by Rebekah in the creative experience teachers in Sebby's school had achieved with Makaton (a language programme using signs and symbols to help people communicate):

**“What really blew us away, we went to see his nativity play at Christmas, and the whole school, all the kids in the nativity were using Makaton. We were just blown away, because they'd never used Makaton before, a lot of these kids. I still get messages off mums now saying, ‘Where can I get more information? I want to learn more, and my kids want to learn more....’”**

Rebekah, Mum to Sebby (aged four)

## Parents aspirations

When asked about the future, there were three common themes of parents' aspirations for their child:

Finding and progressing at a suitable school or nursery



Making friends and building relationships



Impairment-related development



## Finding and progressing at a suitable school or nursery

### Finding a nursery

Parents with pre-nursery aged children aspired for nursery to be a good catalyst for a positive school experience. Unfortunately, parents frequently reported that it was difficult to find information online about a school's accessibility and what support it offers disabled children. Details of staff teams' expertise with disabled children and the accessible facilities within nurseries or schools were particularly lacking. This was a significant barrier for the parents we talked to at a key point in their child's life.

Parents reported that they did not receive any independent advice to help them choose between SEN or mainstream schools or nurseries. Furthermore, neither the EHCP panel or external support providers offered advice before their child started school. Jools outlines a common issue experienced by parents having to find an appropriate school:

**“The most difficulty that we’ve had is it isn’t deemed appropriate for professionals to advise you on which school your child goes to”, and without any support or guidance “it’s a really difficult thing to navigate.”**

Jools, Mum to Zara (aged four)

However, when the proper support was available, finding the right school or nursery was possible, as with Charlotte's search for her sons' placements:

**“We used to have a play specialist that came to see us, who worked quite a lot with one of the children’s centres. She told me that they were opening a new nursery on the common, and it was going to be quite a small but inclusive setting. Because it was new, I think it only had twenty children, and I applied for places for all of them [and] they all got places without the nursery batting an eyelid about the boys or their disabilities...”**

Charlotte, Mum to Raphael and Theodore (aged five)

### **Finding a school**

Finding an appropriate school for their child's needs is an important consideration for parents. Parents were keen for their children to develop and progress to get the best start in life. Some children had missed developmental milestones and faced barriers to their learning and play. Parents were therefore very keen to ensure their children progressed and developed at school as effectively as possible.

All parents had been to a mainstream school. It was quite common for them to wish that their child should also attend a mainstream school and have the chance to share experiences and be encouraged to learn with non-disabled children, such as David's aspirations for this daughter:

**“We would love [Alice] to be able to follow the national curriculum... to go to secondary school with her twin sister...”**

**David, Dad to Alice (aged five)**

For Donna, this ambition is a reality for her son Alfie, and her most important factor in achieving equality:

**“I think, for me personally, it's about being accepted into a mainstream school and making that work for Alfie. I never wanted him to be the boy that is sat in the corner with no friends and things like that... they've just accepted him and taken him under their wing and he's not treated any differently at school...I'm absolutely thrilled that he has fitted in so well to the school and the school life as well.”**

**Donna, Mum of Alfie (aged four)**

However, following research into nurseries and schools, some parents transition towards planning for a Special Education Needs (SEN) school. For example, John and Elizabeth's decision to move their son:

**“We went for a day there to talk to the teachers and talk to the head, and it was fantastic. A fantastic school. They support children from the age of four to 18, which is great. So, there's no transition for him. He's going to be at the same place and it's got a pool for hydrotherapy, it's got dedicated therapy rooms for when professionals come in, he can have his therapy in.”**

John, Dad to James (aged five)

Parents also shared concerns of mainstream secondary schools. They worried about the attitudes of other children, particularly as they got older, and the priority of attainment for SEN children.

As Jools highlights:

**“I do want her to keep developing and keep progressing... there doesn't seem to be a thing of trying to get children to achieve their best... it just seems to be a level of acceptance that SEN kids can bobble along the bottom and that's okay. And I don't think that is okay actually, I think they should have the opportunity to be the best they can be and reach whatever their full potential is.”**

Jools, Mum to Zara (aged four)

## Progressing at school

While at school, an effective EHCP was considered an important enabler for children to progress. Parents wanted regular high-quality EHCPs in place for their children, coupled with supportive one-to-one support from teaching assistants. Richard and Cheryl highlighted how positive this experience can be, pointing out:

**“it’s probably nursery where Alexander has equality. How responsive they’ve been, how amazing they’ve been in helping us get the education, health and care plan, and the support that he’s entitled to. He’s making a lot more progress than we’d anticipated.”**

**Richard and Cheryl, Dad and Mum to Alexander (aged three)**

Everyone aspired for the school environment to be happy and productive. All parents wanted their children to receive a good education, grow friendships and develop as individual and equal to the other children.

Charlotte wished for her son Raphael, “to make new friends and have play dates but also to keep up with his peers at his school, so to be able to go through each of the key stages and be able to do his SATs”.

And Toni’s aspirations for her daughter Daisy, “As I say, she’s highly intelligent, her problem-solving skills are above and beyond her age ability, and always have been. So, I think that one day, she’d make a great academic, because she actually loves learning, as well.”

## Impairment-related development

Parents have aspirations for their child's health to improve, so they could develop and fulfil their potential.

Communication was a priority development area for some parents, due to its importance for facilitating progression at school and in developing relationships. As Richard and Cheryl suggest for their son, Alexander, "speech is going to be just fundamental to his ability to interact and to learn". This is highlighted by the improvements in the speech of Charlotte's son, Theodore, which was "starting to make him feel more confident and be able to communicate more".

Some parents have also been optimistic about learning and applying different communication techniques. For example, Toni uses a digital app with her daughter, Daisy, to enable Daisy to use her voice and communicate more effectively:

**"Even if she can't speak one day, even if she could use PECS, or Proloquo2Go, just some way to help her to communicate, I think is the most important aspiration for Daisy. I think that leads on to making friends, and to develop relationships with her sister and brother."**

Toni, Mum to Daisy (aged four)

## **Making friends and building relationships**

Parents wanted their children to have the best chance to make friends. Such as Jane's wish for her daughter, to have the:

**“opportunity to make friends with other children and hang out with them – enjoy the noise and the playing and the interaction.”**

Jane, Mum to Katryn (aged three)

Parents reported that play date invites for disabled children starting their reception year have been limited, although their children are interacting well.

As Charlotte highlights about her children:

**“The kids really like them at school but, you know, they just aren't invited to play dates which is quite tough.”**

Charlotte, Mum to Felicity (aged two)

Parents also want opportunities for their children to mix with disabled and non-disabled children. They highlighted disabled children's groups and accessible community activities as good places to make friends. Parents even came up with additional and innovative ways to introduce their children to new friends and families:

**“I put together a little postcard with a picture of all three of them and then a little overview... I gave them to the other new parents at school so they could read a little bit about the boys... and they still like having fun and they should be included in stuff which went down really well.”**

Charlotte, Mum to Raphael and Theodore (aged five)

**“I would love Harry to, you know, just grow up, leave school, have friends, go out and just do the things that other young adults do - and we would love for him to be working.”**

Natalie, Mum to Harry (aged four)

# Appendices

# Appendix A: Research objectives, methodology and sampling

## Research objectives

The aim for this research is to explore common equality issues that families of disabled children experience. The year one report covers objectives to:

- map parents' aspirations for their disabled children
- map the change and journeys that families and children go through
- understand the emotional resilience challenges families experience
- identify opportunities to improve support for early years disabled children
- explore 'Getting the Best Start in Life' barriers and enablers
- identify the extra disability related costs families experience and evaluate the Disability Living Allowance journey

## Year one interview journey

The first year interviews were split into three parts.

Firstly, participants prepared timelines for themselves and their children as homework. Timelines covered key life journey highs, lows and aspirations for the future. Secondly, participants described their timelines in an in-depth phone interview.

For part three, participants took part in a home in-depth interview. Participants covered Scope policy topics on 'Getting the Best Start in Life', 'Financial Security' and 'Living the Life I Choose'. Participants covered topics answering semi-structured questions. Stimulus material, pictured above, was also introduced to ask participants:

- To evaluate their equality and inequality experiences on 'Getting the Best Start in Life' issues.
- To recall unprompted and prompted all the extra disability related costs their family pays for.
- To draw an overall satisfaction past, present and future timeline on their most important equality issue.

## Sample breakdown

Participants are part of a panel of 21 families. 23 children are represented by three fathers and 19 mothers. The sample breakdown is shown below<sup>2</sup>:

<b>Total participants</b>	
Families	21
Fathers	3
Mothers	19
BAME families	2
Single parents	2
Disabled parents	3
<b>Location</b>	
Central England	5
North England	7
South England	10
Wales	1
<b>Children</b>	
Boys	12
Girls	11
<b>Disability type</b>	
Autism	7
Hearing	3
Learning	13
Other	4
Physical	12
Vision	6

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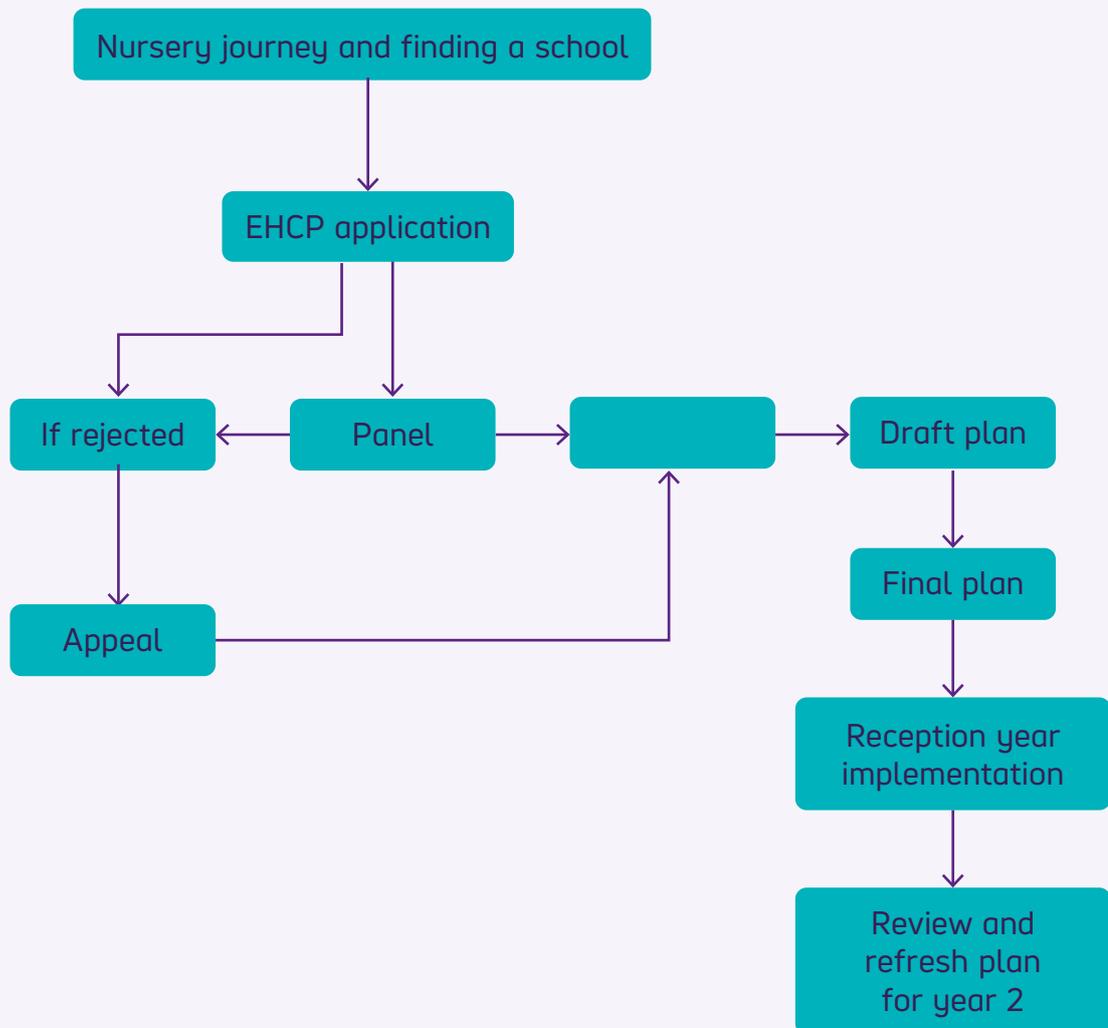
<sup>2</sup> Two BAME (Black and Asian Ethnic Minority) families are taking part. There is one mum and dad taking part together as a couple. Two families in the South of England represent two disabled children each.

## Appendix B: Education, Health and Care Plan (EHCP) journey

The Education, Health and Care Plan (EHCP) is a key support document for providing disabled children integrated support in school. The flow chart below shows the main EHCP journey stages parents reported going through.

The research data specifically outlined parents' experience of the EHCP journey for children starting their reception year. Some of the children had started reception year with EHCPs and some had a variant plan such as a 'statement of needs' or 'sensor'. Parents with pre-nursery age children have not gone through the journey yet.

### Key EHCP journey stages

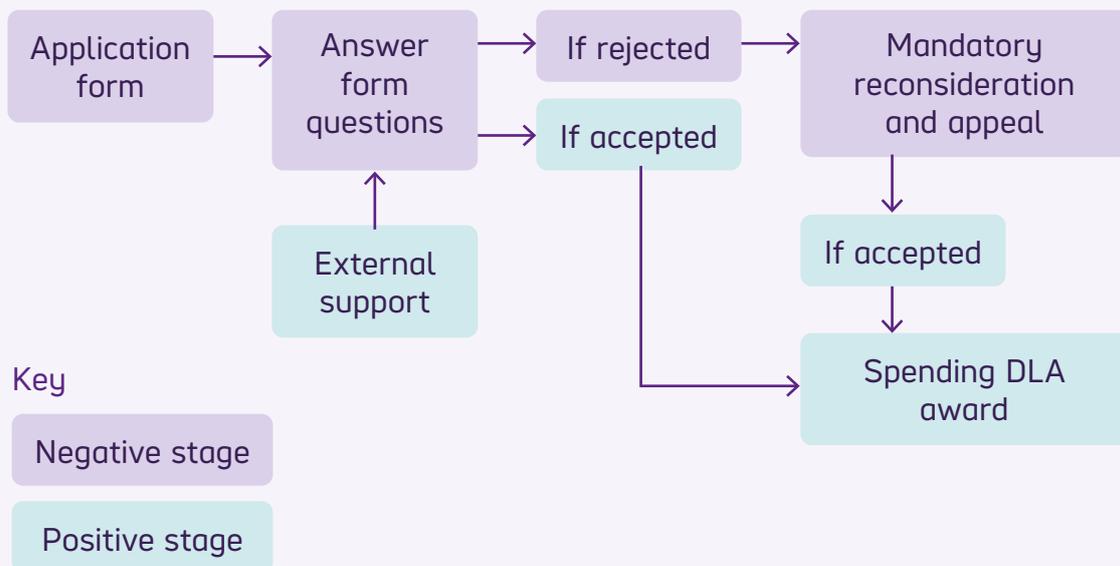


## Appendix C: Disability Living Allowance application journey

Participants reviewed their journey to apply for children’s Disability Living Allowance (DLA). The Department for Work and Pensions (DWP) is responsible for DLA. The allowance helps towards covering extra disability related costs. All participants have been awarded DLA. The process involves completing an application form. If the application is accepted first time, the DWP will proceed to pay the award.

Applicants can move to mandatory reconsideration and appeal stages. This happens when DWP rejects applications or applicants contest the level of their award. Awards are not permanent. Here, the DWP requires applicants to re-apply at different time intervals. The children’s DLA application process has one less stage than the Personal Independence Payment (PIP). There isn’t a face-to-face medical assessment stage with service providers, such as Capita or ATOS.

### Key DLA journey stages





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