



Research among parents of children with disabilities

A research report from Strat7 Jigsaw

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JIGSAW

This report summarises the findings from the recent qualitative research conducted by Jigsaw Research on behalf of People's Partnership.



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Introduction and background

1.1. Introduction

This report summarises the findings from the recent research conducted by Jigsaw Research on behalf of People's Partnership.

It is based on qualitative interviews with parents of children with a disability, some of whom were spoken to via one-to-one interviews, and some of whom took part in a focus group.

As the interviews were all qualitative, the report makes no reference to percentages or proportions but instead draws out the themes highlighted by the interviews, some of which were common to all or most of the parents spoken to, while others were mentioned by only a few of the parents interviewed.

Inevitably, the nature of the disabilities and the life circumstances of the participants in the research were very specific, and this meant that some findings were only relevant to one or two respondents. Where this is the case, the report makes that clear. This also means the report is not able to draw wider conclusions outside of the respondents spoken to, although it is able to highlight a number of areas which may be worthy of further investigation and/or attention by either People's Partnership or other organisations.

1.2. Background and objectives

To highlight the issues facing parents of children with a disability, People's Partnership was looking to research the impact raising a child with a disability has on household finances and, ultimately, retirement provision.

This is in line with...

- a) its purpose of helping people build financial foundations for life, and
- b) its mission of using profits to provide the support that helps people become financially stronger.

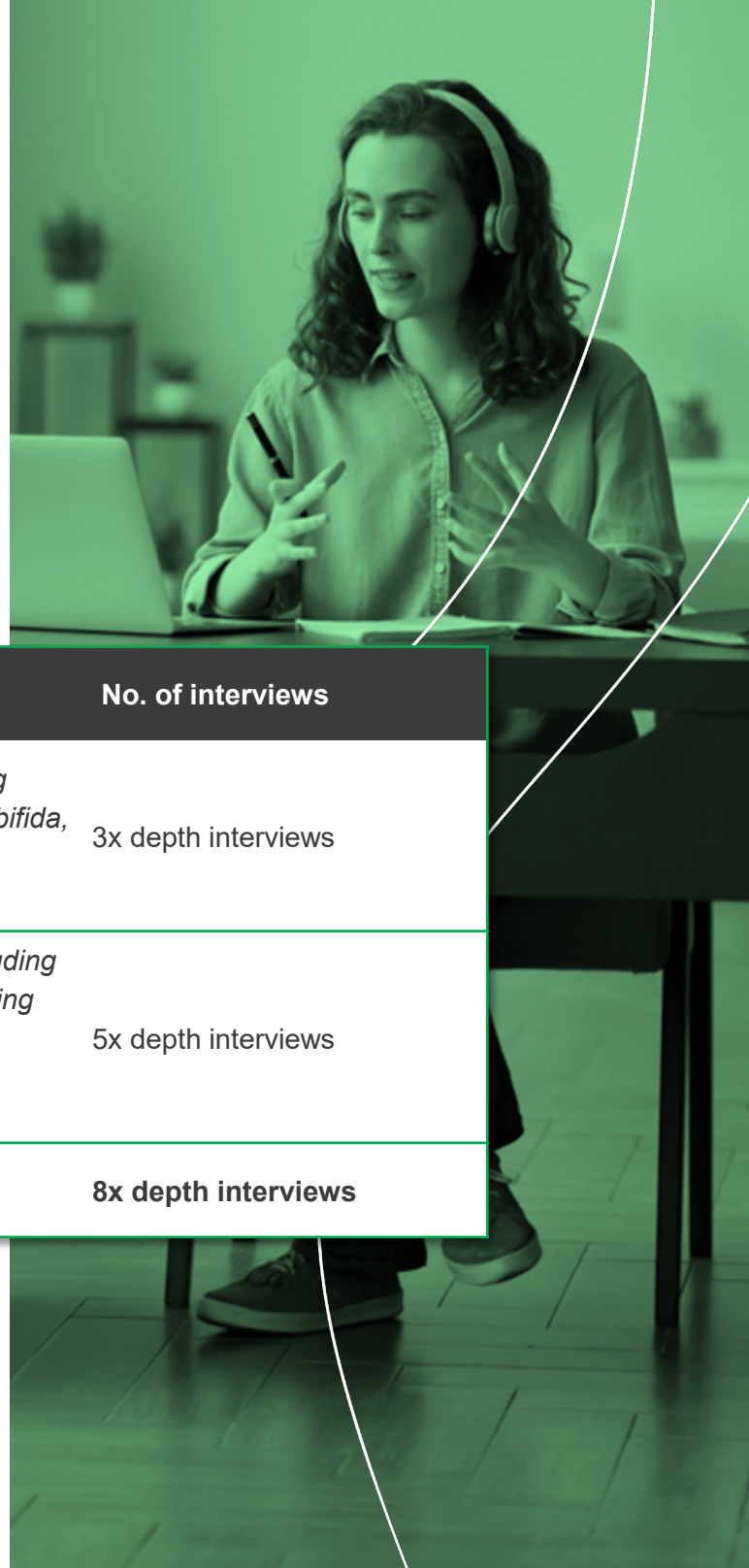
With these strategic aims in mind, People's Partnership was looking to understand how it might best help these parents prepare for their future under financial pressures – for example, losing/reducing one household income and the additional costs associated with the child's condition.

1.3. Research approach

The research comprised a mix of both in-depth interviews and a focus group, as follows:

- 1 x 1½-hour focus group held in Crawley (at People’s Partnership’s offices)
- This was recruited by People’s Partnership and moderated by Jigsaw Research
- 8 x 1-hour in-depth interviews with parents of children with a disability
- All were recruited by Jigsaw Research and conducted via Zoom

With the in-depth interviews, our respondents were raising children with the following types of disability:



Child’s disability	Definition	No. of interviews
More ‘visible’ disabilities	<i>Physical disabilities, including muscular dystrophies, spina bifida, cerebral palsy and acquired injuries.</i>	3x depth interviews
Less ‘visible’ disabilities	<i>Mental health disorders, including behavioural issues and learning difficulties (such as autism, dyslexia, dyspraxia, aphasia/ dysphasia and ADHD).</i>	5x depth interviews
Total		8x depth interviews

The **focus group** comprised six respondents, five of whom had children with less ‘visible’ disabilities (including learning difficulties and neurodiversity issues) and one of whom had a child with a more ‘visible’ or physical challenge.

All fieldwork was conducted during Autumn 2023.

Overall summary

Overall, it was evident across all the interviews and the group discussion that the lives of the parents we spoke to were dominated and, to a great extent, defined by the disability of their child. This was as true of parents of preschool children as it was of those with children in their early 20s.

Bearing this overarching point in mind, it is perhaps not surprising to learn that parents of children with a disability are rarely focused on the long-term future from any perspective (i.e. not just financial). With very little mental space afforded towards even thinking about the future, it follows that not many of the parents spoken to had plans (financial or otherwise) in place for later life.

The key themes that emerged from the research reflected the most pressing concerns of parents of children with a disability:

- Caring responsibilities for child with a disability/special needs children placed significant strain on parents, both physically and mentally. We heard multiple times that parents felt exhausted from the constant demands and lack of any breaks in the caring role they found themselves in
- Feelings of loneliness and/or guilt at the impact the family situation has upon non-disabled/neurotypical siblings
- Difficulties getting adequate support from local authorities, or even just getting the support which is due to them
- Difficulties in navigating the system and understanding exactly what support is due to them combined with frustration at the lack of joined-up information and support for parents in their situation
- Financial pressures upon them, caused by multiple factors

- Loss of earnings through lack of career progression
- Loss of earnings through having to take a lower-paid (part-time) job
- Loss of earnings through only one household income – in a number of cases, the disability of a child had led to relationship breakdown, with the departing partner no longer providing financial support
- Costs involved in getting financial support or care due to them – e.g. legal fees for tribunals/disputes with local authorities
- Increased costs for things like heating, washing, repairs, other extra items, food
- Concerns about the future, although these almost always focused on concern for the disabled child's future if the parent (or parents) was no longer around or unable to care for the child due to their own old age/infirmary

In many cases, there was an acknowledged lack of retirement/late life provision, but it was clear from the interviews that this was not a pressing concern. It was mentioned by respondents in response to questions asked, but it was clear this was not something they had the luxury to worry about or attempt to address.

There was openness to assistance from any organisation (including pension providers), with this assistance generally hoped to go some way towards addressing the concerns itemised above relating to support and in navigating the system to ensure they received all entitlements. Pension providers were not considered top-of-mind providers of this information/support, but all attention/support was seen as welcome.

The remainder of the report expands on the themes outlined above.

Main findings

3.1. Day to day life for parents of a child with a disability

Being a parent of a child with a disability was an all-consuming role for all participants and one which, for many of our respondents, had come to define their identity and day-to-day lives. Caring for a child with a disability was a full-time occupation, regardless of the age of the child and with seemingly little variation depending on the precise nature of the child's disability.

For some of the respondents in the research whose children were classed as neurodivergent, often with a diagnosis of severe autism and ADHD, they were looking after more than one child diagnosed with these conditions. While the severity of the diagnosis might vary from child to child within a family, parenting became an even harder job for these parents, exacerbating many of the issues faced by parents of children with disabilities.

The parents spoken to as part of this research all came across as being 'on top of' the management of the family – a huge part of which was spent looking after the child with disabilities. There was no sense of parents being unable to cope with the day-to-day demands of caring for a child with disabilities, even if those demands were unrelenting and extensive.

However, respondents were unsparing in describing the often chaotic lives and households under their management. Examples of the type of situations and instances which parents had to cope with included:

- Night traumas – the child may be up all night, unable to sleep, afflicted by extreme episodes/dreams, and the parent will be the only person able to comfort them – much like a newborn baby, but over a far greater period
- Severe behavioural issues mean the child needs constant supervision and stimulation

- Destructive behaviour – breaking items around the house
- Preventing the child from (inadvertently) putting themselves in harm's way around the house
- Looking for signs of/trying to address causes of self-harming
- Incontinence – constant soiling of clothes, which then either need to be cleaned or replaced on an abnormally frequent basis
- Managing severity of autism in particular. Parents of children with severe autism spoke of their child being fixated on one thing to the exclusion of everything else. For the parent, this meant having to 'feed' this obsession in order to manage the behaviour of their child. This was both mentally exhausting and financially burdensome for the parent. Some parents of autistic children also spoke of the emotional challenge of caring for a child who is non-verbal and/or who will not tolerate being supervised by anyone other than their parents.
- Being on call 24 hours – even when their disabled child was away from the home (often at a special school or college), the parent had to be permanently on call in case of an issue at the school needing their intervention (such instances seemed to be very frequent)
- Managing external carers/therapists – many of the children in our research were in receipt of an Education, Health and Care Plan (EHCP), which could involve in-home visits by a variety of therapists and specialists. Parents had to be on hand at all times from a safeguarding point of view to supervise these visits.
- Finding time and energy to care for their other non-disabled children.

Specifics of day-to-day household management varied to an extent dependent on the age of the child, but the need for full-time supervision was a constant theme throughout the research. Weekends were, in some senses, more of a burden for parents as all the responsibility fell upon them for the care of their child with a disability. Whether this meant taking the child out somewhere for some stimulation or constant supervision in the home (because the child was not able to function safely outside the house), weekends were a time for constant vigilance by the parents.

The only positive mentioned around weekends was the presence of the respondent's partner to share the family management tasks. However, it should be noted that half of the parents spoken to in the in-depth interviews were single parents, so for these respondents, there was no regular additional support offered on weekends – responsibility always rested with them.

3.2. Difficulties faced in accessing support

At the time of the interview, all of the parents spoken to were relatively experienced in the role of being a parent of a child with a disability. The youngest child with a disability for our parents was four years old and had been diagnosed at two (although the parent was certain of the diagnosis before this), so in that sense, they had over two years of experience dealing with local authorities, the state and other support services. For the rest of the sample, their experience was far greater than this.

Despite this, it was very apparent that parents were not always confident that they were in receipt of all that was due to them. This often stemmed from direct experiences earlier on in the lives of their children, where it was clear that they had missed out on support or were being denied support they felt was due to them.



Indeed, one of the major challenges described by parents was accessing good information and advice from a single, trusted source. While in the past, an organisation like Citizens' Advice might have been a reliable starting point for information, these services were felt to be no longer readily available.

In many cases, parents had learned about support from a range of sources via their own online research or, in a minority of cases, a lucky encounter with someone helpful at the council or their child's school.

There were several different types of support referred to during the interviews, as well as overarching management programmes put in place. We list some of the most relevant ones below:

- EHCP – An Education, Health and Care Plan for children aged up to 25 who need more help than is available through SEN (Special Educational Needs) support. It includes a wide range of support, from school places to therapy and practical help with equipment, etc. This is legally binding on the part of local authorities, etc. (i.e. they have to provide the recommended care).
- DLA – Disability Living Allowance is for a child who has difficulty walking or needs greater care than a child of the same age without disabilities. Across the interviews and group, this was the most common financial support received by parents.
- PIP – Personal Independence Payment is for adults (over 16s) with a long-term physical or mental health condition. This might make everyday tasks or getting around difficult, or both.
- Carer's Allowance – A payment made to anyone caring for someone for at least 35 hours a week.
- Universal Credit – A single payment made to anyone on low income or out of work. Being in receipt of UC can entitle the recipient to other support (e.g., a Motability grant).
- Individual parents, typically the most financially challenged, also mentioned receiving grants from local support organisations or equipment from national charities (e.g. a new bed from BBC Children in Need).

For many of the parents spoken to, particularly those whose children had some form of neurological disability, the biggest hurdle they faced was getting the initial diagnosis. All parents spoke of knowing their child was not like other neurotypical children prior to the official diagnosis. In some cases, this pre-diagnosis period had lasted years.

Diagnosis requires agreement by the parent, an education professional and a healthcare professional. Unless all three parties agree, a diagnosis is not granted, and without diagnosis, it is impossible to access state support services.

Following diagnosis, a number of parents reported ongoing battles with local authorities in order to get an EHCP in place. Although an umbrella term, an EHCP can vary hugely depending on the severity of the diagnosis/condition of the child, as well as simply varying from one local authority to another. On top of that, every EHCP is reviewed on at least an annual basis. This is partly to take account of the child's changing condition but also to protect the local authorities' scarce resources. For the parent, this means never being able to rely on long-term support, as it is subject to constant review.

Some of the parents also spoke of a reluctance on the part of local authorities to offer an EHCP that fully acknowledged the needs of their child. This might mean not offering access to certain therapies or only offering special education during certain hours. It could also mean only offering a place at a mainstream school with SEN provision when the child clearly could not function in such an environment.

These disputes could go on for a long time, with a small number of respondents reporting the need to enlist legal representation in order to achieve their aims. This legal support came at a cost – in one case, necessitating a second mortgage in order to pay legal fees running into the tens of thousands. Parents spoke of repeatedly going to the Local Authority Ombudsman, repeatedly winning their case, only to go through this cycle again and again.

As well as the financial toll this took upon household finances, these experiences placed a huge mental strain upon parents who were already under severe stress coping with the day-to-day management of their child and wider family.

There seemed to be fewer reported issues in relation to the various types of financial support mentioned earlier, although again, DLA was reported as being assessed on a scale, and often, the parents' view of their child's disability did not always match the official view when it came to the level of DLA award.

There were relatively few mentions of specific equipment needs or adaptations needing to be made to the house. One respondent spoke of receiving a disabled facilities grant of £8k – £ to adapt the bathroom and install a stairlift. This same family were also in receipt of financial assistance to convert a car under the Motability scheme.

Overall, the parents tended to give the impression that interacting with the state/local authorities was an energy-sapping, time-consuming experience.

Specific negative or onerous experiences cited by respondents included:

- Having to deal with apparently disconnected departments within the same local authority. For example, parents might succeed in securing a place at a special school for their child with the education department but then effectively have to start again making their case with the transport department to secure a taxi for their child to and from the school every day
- Struggling to secure the support of, for example, occupational therapists because of staff shortages and personnel moving on to other roles, etc. There was a widespread belief that the pandemic has had a significant negative impact on services.



Across the interviews and group, many parents felt that too many families are chasing support from overstretched, under-resourced and under-funded services. Parents of neurodiverse children often believed that services had become more difficult to access since the pandemic because of the growth in neurodiversity diagnoses in the country during that time.

Alongside this, prior experience left many of them feeling unsure that they were in receipt of all that they were entitled to, which only added to the mental stress they openly admitted to feeling.

3.3. Financial impact of being a parent of a child with a disability

Among almost everyone spoken to as part of the in-depth interviews, the number one financial impact they felt was linked to being a parent of a child with a disability was upon their own career progression and ability to earn. This was expressed either as a direct loss of earnings (i.e. I'm not able to work and haven't been since the birth of my child) or as an opportunity cost (i.e. I would have been able to earn more than I have done due to my family circumstances). Either way, this loss was keenly felt and, although incalculable, felt to run into the tens of thousands of pounds.

Some of our respondents had not worked since the birth of their child with a disability; others were working but had decided that they could not take on more responsibility at work as they needed to focus on the child. In a couple of cases, parents had switched from well-paid but demanding careers to less well-paid and more flexible jobs to enable them to dedicate time to their child with a disability.

Finally, we spoke to others who had worked until they found it impossible to balance the demands of their employment role with the demands of being a parent of a child with a disability. The job, in this case, became a casualty of circumstances, often because asking for time off for their child became awkward or came to be resented by their employer.

It should be noted that among the employees at People's Partnership, responses were slightly different. By definition, everyone taking part in this group was in employment, some in quite senior roles. In that sense, they often corresponded to the partners of the respondents we spoke to in the in-depth interviews, who said their partners were in employment and helped when they could but also had to focus on bringing income into the household. That said, even among this group, we did hear some mention of parents self-regulating their ambition, not feeling able to go for more senior roles, for fear of the time pressure this would place them under and the incompatibility of this with their home life.

This point was reflected by respondents in the in-depth interviews where they had a partner in employment. Their view was that the second most important impact upon household finances of having a child with a disability was upon their partner's ability to maximise their earning potential. Again, this was not quantifiable, but very definitely felt.

Even when in receipt of all state help, plus in some cases a main income from one of the parents, it was still clear that household finances were very tight. It was common to hear respondents say it was years since they had been able to afford any kind of holiday for themselves and the family. The focus was on ensuring bills were paid, and the extra costs incurred through having a child with a disability were also met. The rising cost of living was only exacerbating these issues.

These extra costs varied depending on the age of the child and the nature of the disability, but overall, they tended to fall into one or more of the following categories:



Higher than normal household bills. Some parents spoke of needing to keep the heating on all year around (or at least longer than average households) because their child was susceptible to the cold. Others talked of a constant need to be washing clothes for their child, adding considerably to energy costs.



Higher than normal food costs. Some parents mentioned specific dietary requirements for their children. This could include only cooking from fresh ingredients or needing to buy only very specific (expensive) food brands for their child – e.g. oat milk for a lactose-intolerant child.



Meeting the very specific demands of their autistic child. Parents of autistic children often cited a very specific topic which their child was obsessed with to the exclusion of anything else. From a behaviour management point of view, but also from a quality of life point of view, parents felt obliged to fund this obsession as far as possible. This could be very expensive – e.g. two parents said their children were fashion brand obsessed and would only wear very specific labels, which would change and were always expensive.



Frequently replacing broken items in the house caused by the child's challenging behaviour. Examples given included toys, furniture, televisions, bathroom fixtures, and white goods.

Some mention of specific equipment and private therapy treatments where the NHS waiting list was too long. Equipment could include wheelchairs, adapting bathrooms and stairs.



As mentioned earlier, paying for legal fees in order to pursue cases against the local authority in an attempt to get a diagnosis or bring the EHCP up to the level they felt it should be for their child's condition.



Extra costs associated with travelling to appointments/visiting special schools/colleges, etc.



In the group, some respondents mentioned that their relatively good salaries resulted in them having to pay for things that other less affluent parents received for free – e.g. having to provide a packed lunch for their child at their day centre while others received a free lunch from the institution. This was taken as another sign that the local authority only has the resources to provide full support for the most needy in the community.

3.4. Long term planning

One of the most consistent findings across the interviews was the absence of almost any long-term planning among the parents spoken to. This was a very common theme among all eight of the parents spoken to in the in-depth interviews, although less so among the focus group of People's Partnership employees, where financial planning is at the heart of the culture of the business.

First and foremost, parents felt unable to devote any headspace to thinking about future plans. This covered both financial planning for their future but also (and arguably more importantly) any aspiration or idea of what the future might look like. If you have no idea of what future you would ideally like or what it might look like, it becomes much harder to even think about how you might plan financially for later life.

In any event, as the previous sections have shown, the parents spoken to were all the primary caregivers for their child, and this was such an all-consuming task that the idea of planning for the future was unrealistic in their eyes. During the interviews, the respondents often said they knew they should have financial plans in place but that they hadn't thought about it and couldn't imagine how or where they would start to save for the future. It was clear to us that even this response was only prompted by our questions – future financial planning was not something they ever thought about or discussed with their partners.

When asked about the future, the one overwhelming fear concerned what would happen to their child with a disability if something should happen to the parent(s). This was naturally more keenly felt among single parents, but all mentioned it to some extent.

This revealed another near-universal response, which was a firm belief that their child with a disability would always be completely or partially dependent on them. None of our respondents in the in-depth interviews, and few in the group, could imagine a future where the child was not living with them. Many could not imagine them ever being in paid employment.

These beliefs had profound effects on the parents' view of their future. The idea of 'retirement' was completely unattainable or even undesirable. For many, the question would be 'retirement from what?' but more pertinently, they saw themselves as always needing to look after their child to a greater or lesser extent.

In one or two cases, parents imagined they wouldn't have a retirement in the traditional sense but that their later life would involve some kind of family enterprise involving their now adult child. For example, one respondent thought that he and his wife would move to the country and run (and live off) an animal sanctuary business so that his autistic daughter, who has an affinity with animals, would have a meaningful role in adult life.

Many parents (especially those in the in-depth interviews) spoke of having very little in the way of pensions or any kind of long-term savings. Some parents had worked previously and thought they might have a small pension pot somewhere, but not one that would pay out anything meaningful. One, who had given up work as a teacher to care for her child, knew that the Teacher's Pension scheme was a final salary one and was worried that her inability to re-enter the workforce would mean her final salary would be assessed as 'zero'.

Even those respondents who had partners in full-time work had not discussed their partners' pension arrangements and what that might mean for the family. The strong view was that they knew it would not be enough, but the day-to-day concerns were far more pressing.

The focus group made up of People's Partnership employees were not surprisingly much more aware of their pensions and longer-term financial planning more generally.

Nevertheless, even here, we heard just how hard it was to save more than the minimum into long-term savings because of the extra expense/lost career earnings that comes from having a child with a disability.

Linked to discussions around pensions provision more widely, we heard some parents say that although they couldn't afford to pay into a pension, they had taken out life insurance. Given the fear mentioned earlier of what would happen to their child if they were not around, life insurance assumed a much greater importance than it would for the average family. It was clear that this product was providing some peace of mind when they thought of the future.

Beyond this, where any mental space was focused on finances and the future, it tended to focus on the mortgage. Many parents talked of paying off the mortgage for many years to come – arguably much further into later life than average. This was viewed as a much greater priority than building up a pension pot – and the family home was often talked about as being the only realistic asset they would have in later life. Again, this was talked about in terms of an inheritance rather than something that could provide them with an income in later life.



3.5. What help could pension providers offer parents of children with a disability?

None of the parents spoken to during the in-depth interviews would think of going to a pension provider for information relevant to their specific circumstances. This was partly due to the fact that none had a relationship with a pension provider – even those who said they did have a small pension pot somewhere did not know who it was with.

However, as described earlier, it was also very clear that many parents felt that there was no one place where you could find information that was helpful for parents of children with a disability. Whether that was information relating to existing support available to them, other types of support (i.e not state-funded, but possibly charity-funded) or financial help and advice – there was a strong sense that no one organisation offered this in one place.

From that point of view, although parents would not expect a pension company to offer this kind of one-stop shop of information for parents of children with a disability, they would be extremely grateful to any organisation (pension providers included) that did offer this kind of facility.

As mentioned, Citizens' Advice was felt to be the closest to offering a one-stop shop, but without the expert financial perspective, it was felt a pension provider could offer. The types of information that respondents were looking for included:

- Advice and information relating to all types of state support potentially available to them and their child. This can mean relevant links rather than offering an advice telephone service.
- Advice and information relating to possible charities who may be able to offer further support. E.g Mencap, MIND, etc. An exhaustive list covering all types of disability would be impossible to compile, but the larger charities covering the more common conditions would still be a good start.
 - One parent mentioned Family Fund (www.familyfund.org.uk/), which they had only very recently heard about. No other parents mentioned this, but it is possible this kind of broad charity offering help to all parents of children with a disability, could be a good partner for a company like People's Partnership.
- Offer guidance on managing finances in light of the extra costs and uncertainties involved in caring for a child with a disability
- Develop financial planning/savings products with their needs in mind, as it was felt existing products don't allow for their circumstances.
 - In particular, flexibility was seen as a key feature they would like to see. Their lives were unpredictable, and the need for payment (contribution) holidays was mentioned, as was the ability to only pay what you could afford rather than a set amount each month.
- Advice on how to plan for their financial futures
 - taking into account priorities such as paying off the mortgage and/or funding long-term care for their child ahead of more traditional retirement planning
 - A few parents did express hope of returning to the workplace when their child was older, albeit working reduced and irregular hours. They wanted to see savings products that took into account their earning from a much later point in life than traditional pension products, which assumed consistent earning from a young age.

- Publish case studies showing people like them and how the pension provider has helped them with planning their financial futures.

Finally, it was hoped that pension providers could also be a lobbying force on behalf of parents of children with a disability.

This was not because they particularly expected pension companies to do this, but there was a strong sense that no one was doing this at the moment, and if a pension provider wanted to show commitment, this was a good way to demonstrate this.

Parents spoke of lobbying both the government and employers.



3.6. What help could employers offer parents of children with a disability?

Although all the parents spoken to felt their child with a disability was going to be dependent on them to a greater or lesser extent permanently, this did not stop many of the parents from expressing the hope that they could return to the workplace at some point. Many expressed trepidation at this thought – they had often been out of the workplace for several years, up to 20 or more in some cases. They acknowledged they lacked confidence in their abilities to re-enter the workplace, as well as not seeing a clear solution as to how they could balance work while still caring for their child.

Aside from these very pressing concerns, parents also expressed doubts that many employers would want to employ someone in their circumstances. Indeed, these concerns were what had made some leave the workplace in the first place. When questioned further, these parents said they would like the following from an ideal future employer:

- Flexible working arrangements, as far as possible so the parent could choose the hours that suited them, as long as the work got done
- Empathy. Parents spoke of the guilt they had felt at letting colleagues down in previous roles when they had to leave work suddenly to attend to their child. It was felt this was partly due to the culture of the workplace, where organisational goals were all-important, and no real consideration was given to the individual. Anyone re-entering the workplace ideally wanted an employer that explicitly addressed and dismissed these feelings of guilt – making sure all employees knew that the view from the top was that there was no judgment being made if someone had to leave to look after their child.

- Offer sabbaticals if the situation becomes acute, rather than allow someone to quit their job because they feel they have no alternative.
- Provide paid carers' leave in addition to standard sick/holiday pay to help cover medical appointments and care needs.
- Offer EAP (Employee Assistance Programmes) schemes and mental health support to help parents cope with the stresses and strains of being a working carer.

A number of the respondents spoken to were only looking at work in the education and care sector, partly due to the more reasonable hours on offer and the term-time working schedule - but also because it was a topic close to their hearts and they felt that through their personal experience, they had a lot to offer.

Some parents in employment acknowledged that their employers had been highly understanding of their circumstances and needs, allowing them to work flexibly as required. But they also felt that this support had been entirely at the discretion of their line manager, who happened to be a "nice, understanding guy". What would be more supportive and reliable would be an official company policy regarding parents of children with a disability, something enshrined in the constitution of the business.



Conclusions

Overall, this research has highlighted the significant pressures faced by parents of children with disabilities. It is clear that for many parents, looking after a child with disabilities is a full-time, 24/7 existence, with all the physical and mental stress that comes with that, as well as the financial impacts.

Where there are two parents, this is mitigated to some extent, at least at weekends when the second parent can provide additional help with the child. However, the overall picture in both one- and two-parent families is one of immense pressure and short-term coping strategies to provide the best possible upbringing for all children in the household.

Parents of children with disabilities do not feel their situation is widely talked about or understood by society as a whole. They talk of it being a lonely role, with very few able to understand what they are going through. This is a group in society in need of allies.

In these circumstances, it is no surprise that they welcome the idea of a pension provider taking an interest in their circumstances and potentially offering to help in some way. A pension provider would not be their first place to go for such help, but if it is being offered, they will gladly accept. The advice a pensions provider could usefully provide chiefly relates to financial planning, of course, but broader advice – on the practical, emotional and financial support they can access or are entitled to from other sources – would also be valuable.

At the moment, the idea of long-term future planning feels like a luxury of both time and money that few can afford. However, if an organisation is willing to at least do some of the thinking for them, this would be greatly appreciated. Offering an additional space to discuss/think about the future would be something everyone spoken to as part of this research would welcome.

Thanks to all the participants in the qualitative interviews
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