



# Under pressure

The relationships of UK parents who have a child with a learning disability

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# Forewords

## Chris Sherwood, Chief Executive, Relate

Good quality relationships with partners, families, and friends matter to all of us and are central to our health and wellbeing. Our landmark *The Way We Are Now* survey of the UK's relationships therefore provides an important window into how our relationships are going and the pressures they're facing. But while all relationships undergo change and experience strain from time to time, particular groups in society may face additional or especially intense pressures on their relationships, and it's important we understand these experiences. This is why Relate and Relationships Scotland were delighted to partner with Mencap to produce this report – the latest in the series of reports from our *The Way We Are Now* research – which looks more closely at the couple, family and social relationships of people who have a child with a learning disability.

The picture it presents is rather bleak. We all face challenges in our relationships, but our research shows, sadly, that parents who have a child with a learning disability face additional pressures – it's telling that money worries in particular are more acute for these families.

Unhappy relationships can have a terrible impact on couples and their children, but it doesn't have to be this way. That's why we've joined forces with Relationships Scotland and Mencap to call for a package of support for parents of children with a learning disability, including better access to short breaks services, improved childcare support for parents of children with a learning disability and targeted relationship support. At Relate, we know the difference counselling can make and we need to ensure it's available to families who need it, as part of a wider package of support.

## Jan Tregelles, Chief Executive, Mencap

As a society, we know very little about learning disability. Myths and misunderstanding obscure the truth about what life with a learning disability means. Among the biggest of these myths is that giving birth to a child with a learning disability means automatically facing a life of struggle and hardship.

For many parents we know that the opposite is often true. But it does come with challenges. Relate's research exposes some of the unnecessary strains parents of children with a learning disability often face, and importantly, how we can overcome these.

For all parents having a child is a mix of excitement and fear. When will they say their first word, will they have friends, what will their talents be, when will I next get to the cinema or pub? The questions are the same when you have a child with a learning disability. At Mencap it's our priority to ensure parents and their children get the best possible support during those formative early years, so these questions have easy answers.

Relate's research shows many of the concerns that parents of children with a learning disability have are the same as for parents without a child with a learning disability. However, it also brings to life in a stark way the added pressures that having a child with a learning disability can bring.

We know, for example, raising a child with a disability is likely to mean additional costs,

and that caring for a child with a learning disability may involve more hours or specialist skills. The Government has a duty to help, and vital services such as short breaks can be the difference between families reaching breaking point or not. Mencap's own research suggests that access to support (or lack of it) is a key strain on families. Despite this, many councils struggle to provide adequate access to short breaks, meaning families suffer unnecessarily.

We also know that there can be times when raising a child with a learning disability can cause a strain on mental health. Mencap's research revealed how 70% of parents have felt unwelcome when in public with their child who has a learning disability. This fear combined with not having friends with relatable experiences can feel isolating. Combined with attitudes of the public to disability, this can lead to parents shutting themselves away.

We've heard stories of parents afraid to attend to go out in public or attend events such as their best friend's wedding over fear of other people's reactions to their child. Every parent should have the right to feel proud of their own child, which is why shifting attitudes to learning disability is one of Mencap's biggest priorities.

This research exposes important gaps where parents are not getting the added support they need (and are often legally entitled to), and shows how this can put unnecessary strains on relationships.

We constantly see warm, rich relationships between parents and children. We hear stories of the joy, new perspectives and often humour that having a child with a learning disability has brought. These experiences contradict the highly negative rhetoric we know people hear at diagnosis from the media, friends or even medical professionals. The strains come from inadequate support, and right now too many parents are being failed. Far more needs to be done to provide the correct interventions and financial support.

Local authorities must meet their statutory obligations to provide necessary support to children. They must also correctly assess parents' need for extra support and provide them with accurate and easily accessible information about learning disability and the crucial support to which parents are entitled so they don't miss out.

While Relate's research shows that families can have negative experiences, it also shows that having a child with a learning disability is not the guarantee of hardship that many would have us believe. In fact, it is the making of many families. Where there are strains, these have solutions and, if they are tackled head on, we can help families and provide their child with the best possible chance of flourishing now and in the future.

# Summary

Good quality, supportive relationships are vital for all of us as ingredients of our health and wellbeing. But they can be particularly essential for parents of children with a learning disability. For these parents, close and supportive relationships with a partner, family and friends may protect against the risks of poorer mental and physical health, isolation, and other impacts that may come from providing round-the-clock care for children with a learning disability.

Given the importance of personal relationships, it is vital that we understand how these relationships are going today. Are they of good quality? What specific pressures are they facing? How do they fare in comparison to the relationships of families whose children do not have a learning disability? Sadly, our research paints a rather bleak picture. It shows that the relationships of many parents with their partners, friends, family members and others suffer acutely, with loneliness and isolation being significant problems.

This research report is the third in a series presenting findings from our landmark *The Way We Are Now* survey of more than 5,000 people across the UK, that provides a unique window into the state of the country's relationships. In it, we look at the couple, family and wider social relationships of families with a child with a learning disability: that includes parents' relationships at work and work-life balance as well as relationships with friends and neighbours.

All relationships, of course, go through ups and downs with the general vicissitudes of life. But families who care for a child with a learning disability often face particular challenges stemming from their specific caring role. Among these are, for example, bearing the financial costs of more intensive care and the income forgone through giving up work; the physical, psychological and emotional strains associated with the additional caring demands; reduced time spent together as a couple; difficulties dealing with professionals and services and/or lack of suitable support; and, finally, isolation.

Our data indicate that, if not effectively addressed, these pressures can negatively impact upon the couple, family and social relationships of parents with children with a learning disability, with knock-on effects on their wellbeing. The survey sample showed that parents of a child with a learning disability were:

- More likely to experience lower relationship quality: over a third of parents of children with a learning disability were in distressed relationships, and they were more likely to be in distressed relationships than other parents (34% in distressed relationships compared to 26% of other parents);
- More than a third more likely to cite money worries as a source of strain, with 39% doing so;
- More likely to feel relationship strain as a result of childcare or bringing up children (18% compared to 12% of other families)
- Less likely to find time for 'date nights': nearly a quarter (24%) only have date nights once a year or less, compared to less than a fifth (17%) of other parents;
- More likely to have no close friends: almost one in six (17%) said they have no close friends;
- More likely to feel lonely: over a fifth (22%) said they felt lonely often/all the time –

almost 70% higher than the proportion of other parents;

- Less likely to feel good about themselves – 40% more likely to never/rarely feel good about themselves;
- Almost twice as likely to say that they felt down, depressed or hopeless at least ‘often’: 27% said they felt down/depressed/hopeless often or all the time, compared to 14% of other parents;
- Less likely to report good relationships with their own parents, children, and siblings: 75% had a good relationship with their mother (compared to 81% of other parents), 71% reported a good relationship with their father (compared to 78%), 88% reported good relationships with children (compared to 93%), and 65% had good relationships with siblings (compared to 72%);
- Less likely to have good relationships with friends (78% reported good relationships compared to 85% of other parents), neighbours (62% vs. 66%), work colleagues (69% vs. 79%) and bosses (57% vs. 66%); and
- More likely to feel pressured to be available at work and prioritise work over caring responsibilities (38% agreed their employer thinks work should be the priority in a person’s life compared to 32% of other parents; 40% felt their employer’s ideal employee is available 24 hours a day compared to 31% of other parents).

Our data also show starkly just how much support many families may need as parents strive to balance parenting with other care responsibilities and in many cases their own support needs. Almost four in ten (39%) parents with a child with a learning disability in our survey also provided care for others besides their own children, and almost half (49%) reported that they were themselves limited by a disability or long term condition.

The clear implication of our latest data (which is in line with previous research within which we locate our findings) is that caring for a child with a learning disability can place additional pressures on relationships for many families over and above those that every family faces, and, therefore, key stresses on these families such as money worries and childcare problems can have an even more significant impact on their wellbeing.

However, things need not be this way. We believe that, with the right support, parents who have children with a learning disability can enjoy strong, good quality couple, family and social relationships. And given the importance of these relationships for every individual’s health and wellbeing, there are compelling reasons for policy-makers to address the causes of additional stress on families who have children with a learning disability and to support and strengthen their relationships to improve their wellbeing.

Not only is there an established link between relationships and health and wellbeing, there are also all the costs that result from responding to poor health. Hence, we believe that providing better support for the parents involved – to reduce the stressors which can place additional pressure on relationships and therefore help to prevent relationship difficulties, and to improve the way in which services respond to relationship difficulties when they appear – could not just improve families’ wellbeing but may well provide longer term returns for the tax-payer. Specifically, Relate and Mencap are calling in England and Wales for:

- Good quality information for parents on what support is available to them;
- Effective identification and assessment of parents and family carers of people

with a learning disability;

- Increased take up of benefits which 'passport' you to other benefits for parent carers and disabled children
- Short 'respite' breaks for parents;
- Better childcare support for families of children with a learning disability; and
- Targeted relationship support for parents of children with a learning disability.

# Introduction

## Relationships matter

Our personal relationships matter to us all. When they're going well, they're a vital source of support and crucial pillars of our personal identity, life satisfaction and wellbeing. Unsurprisingly, then, when the Office for National Statistics asked the general public about what matters most to wellbeing, relationships with family and with friends were listed top, jointly with health (89% for both).<sup>1</sup>

Equally, when our relationships are in a poor state – for example, under pressures such as work stress, money worries, lack of time, and other stressful life events – we feel an immediate impact: strained or distressed relationships can be detrimental to our mental and physical health.

All couple relationships go through periods of change over the life course – moving in together, getting married, having children, taking on caring responsibilities, going experiencing bereavement, retiring from work, for example. And most relationships will come under strain at some point as partners adjust to these changes and negotiate the other challenges life throws up.

Families who care for a child with a learning disability often face additional and particular challenges. They have to adjust to new roles. They may face particular financial pressures due to the costs of more intensive care and, potentially, loss of income if they give up work or reduce their hours to care for their child. They face additional difficulties in accessing childcare. They may also face particular physical, psychological and emotional strains associated with the additional caring demands and in coming to terms with their child's disability. They may have less time to spend together as a couple or family – and less time for themselves. They may experience difficulties dealing with professionals and services who may not understand their situations, or difficulties in obtaining suitable support services. Finally, they may feel isolated as individuals as a consequence of dealing with all of these pressures. These challenges can exacerbate any existing pressures on a relationship which emerge through the ordinary course of life. And, in turn, weakened or strained relationships reduce parents' resilience and ability to cope.

There's now compelling evidence that relationships are vital to our health. A wealth of research attests to the benefits of good quality relationships for adults' and children's mental and physical health.<sup>2</sup> People in good quality relationships have lower blood pressure than those in poorer quality relationships,<sup>3</sup> for instance, while relationship stress increases the risk of recurrent coronary events.<sup>4</sup> Relationship quality even predicts patient survival among those with chronic heart failure.<sup>5</sup>

Equally, several decades' international research shows the importance of family relationships for children's long-term outcomes and life chances. For example, a large body of research shows the quality of the relationship between parents affects interactions between parent and child as well as child behavioural and cognitive outcomes:<sup>6</sup> good quality, low-conflict relationships are associated with positive parent-child relationships and positive child outcomes.<sup>7</sup> Children growing up with parents who have good quality relationships and low parental conflict (whether couples or separated partners)<sup>8</sup> enjoy better physical and mental health,<sup>9</sup> better emotional wellbeing,<sup>10</sup> higher

academic attainment,<sup>11</sup> and a lower likelihood of engaging in risky behaviours.<sup>12</sup> A recent evidence review by Professor Gordon Harold of the University of Sussex for the Early Intervention Foundation found that the quality of parental relationships has a significant impact on children's wellbeing – both in intact and separated families – and concluded that the quality of the inter-parental relationship is a 'primary influence' on children's outcomes.<sup>13</sup>

Children who grow up in poorer quality relationships, however, experience poorer mental health and behaviour problems,<sup>14</sup> and studies show inter-parental conflict can result in impaired parent-child relationships and can affect children's and adolescents' wellbeing and development.<sup>15</sup> Research also shows specifically the negative impact of poor quality parental relationships on children with a learning disability: one study found that children with a learning disability whose mothers suffered high levels of psychological distress from relationship problems did worse on measures of behavioural adjustment six years later than other children.<sup>16</sup>

So good quality, supportive relationships are particularly important for parents of children with a learning disability. For these parents, a supportive relationship can help protect against the increased risks of depression and parenting stress to which they may well be subject.<sup>17</sup>

How many parents are we talking about here? There is no definitive record of the number of people who have a learning disability in the UK, as comprehensive information on the prevalence of learning disabilities is not recorded. The Learning Disabilities Observatory, however, has estimated that in England in 2015 there were 1,087,100 people (of any age) with a learning disability.<sup>18</sup> If we extrapolate from this to the whole of the UK, then there are between 1.3 and 1.4 million people with a learning disability in the UK in total and approximately 270,000 children with a learning disability. And in our sample, nine per cent of parents reported that they had a child who has a learning disability.

# Existing evidence on the impact of parenting disabled children on family relationships

Before we look at our data, we first give an overview of existing research into the impacts on family relationships of parenting disabled children. A number of previous studies have examined the impact on family life and relationships of parenting children who have physical and/or a learning disability. While we do not intend in this report to provide a comprehensive review of the literature, it may nonetheless be helpful to situate our findings from our *The Way We Are Now* survey in the context of some of the wider research findings.

The current evidence base on relationships of families caring for a child solely with a learning disability is quite small. It is important to note that, consequently, we have broadened out this evidence review to include evidence on disability more generally. Of course, many of the experiences of families with a child who is physically disabled may differ in nature from those who have children with a learning disability (and some children may have both a learning disability and also be physically disabled). Hence, we are careful to distinguish in this report where the evidence relates specifically to learning disability and where it relates to other disabilities.

We should also recognise, of course, that types of learning disability differ greatly – and we may expect any impacts on family relationships to similarly vary. A child with a mild disability may be able to live independently with quite minimal support, for example, whereas a child with profound and multiple learning disabilities may require round-the-clock care and need significant help with daily living.

## Does parenting a disabled child increase risk of divorce/separation and of relationship distress?

A report by OnePlusOne in 2007 provided a useful review of the literature on disabled children and their parents' relationships. It found specific evidence that couples caring for a child with a disability are at greater risk of marital problems and divorce. This was due to the additional pressures, including managing traditional gender roles, lack of time for one another, dealing with grief over the loss of the 'hoped for' baby, adjusting to changes as the child grows up, and significant financial pressures.<sup>19</sup> Overall, the report concluded that studies have recorded higher rates of divorce or separation for parents of disabled children – although studies looking specifically at relationship quality have been less conclusive.

For example, the 2004 Families and Children's Study in the UK found that a greater proportion of disabled children lived in lone-parent families, suggesting an increased likelihood of parental relationship breakdown or a lower likelihood of parental relationships leading to marriage or long-term cohabitation.<sup>20</sup> Similarly, studies have noted an increased risk of parental divorce for families with disabled children.<sup>21</sup> A meta-analysis reviewing the findings of a number of studies in 2004 found that couples with a disabled child had poorer marital adjustment (a measure of marital quality). However the

difference was small, equating to a six per cent increase in the risk of divorce or separation.<sup>22</sup> Other studies tell a similar story. They find, for example, that parents of children with chronic illnesses experienced more marital distress than parents of other children,<sup>23</sup> and that parents of disabled children experience intensified parenting stress, poorer mental health, decreased leisure time and they are more likely to divorce.<sup>24</sup> A more recent study also found that particular characteristics of disabled children could affect the whole family over time, and parents of children with emotional disturbances were 81% more likely to get divorced.<sup>25</sup>

This evidence must be balanced, however, with many other studies which have found *no differences* in terms of marital distress between parents with and without disabled children.<sup>26</sup> Significantly, no correlation was found by the first study using a large, nationally representative sample (in the United States) rather than the small, clinical samples previously used.<sup>27</sup> And a comprehensive review of the evidence in 2004 also cited many systematic studies which found no differences between parents of disabled children and parents of non-disabled children, in terms of either relationship quality and divorce or separation: that review concluded that ‘evidence for increased marital discord and divorce rates among parents of disabled children is weak and inconsistent’.<sup>28</sup>

## How does parenting disabled children affect parents’ relationships?

While the evidence of the impact on parents’ relationship quality, and perhaps even on divorce rates, may not be conclusive, the existing research does indicate a number of particular pressures on parents of disabled children. UK research with families with disabled children in 2011, for example, found that 72% experienced mental health problems such as anxiety, depression or emotional breakdown due to isolation. Almost half had felt so unwell that they had asked their GP for medication or had seen a counsellor, and one in five reported that isolation had led to the break-up of their family life.<sup>29</sup>

Parenthood in general can reduce the time partners have for each other. Unsurprisingly, therefore, parents of children with a learning disability – whose care needs may be more intensive than other children – may be particularly affected by a lack of time to spend together as a couple. One study found 90% of parents of a child with a learning disability said they did not have enough time to spend together.<sup>30</sup> Other research shows how a lack of time together due to the day-to-day practicalities of providing intensive, round-the-clock care placed greater strain on parents of disabled children; many parents in the research reported they’d not been out with their partners for years either as they were unable to find someone to babysit or could not afford to go out.<sup>31</sup>

The literature also indicates that parents can experience grief following the diagnosis of a disability, mourning the lost ‘hoped for’ baby.<sup>32</sup> Other studies indicate that parents may become depressed, or experience anger, denial, fear, self-blame and even emotional breakdown.<sup>33</sup> Research shows that some parents report that resolving the emotional impacts and addressing practical concerns of caring for one or more children changed them as people.<sup>34</sup> For example, many parents (typically mothers) are unable to return to work due to the difficulties finding suitable or affordable care services. Many parents who do continue to work may change work patterns or work fewer hours – with implications for their careers and family finances. Households with a disabled family member are more

likely to not be working, or to work fewer hours, and the level of worklessness is much higher for households with disabled children: 38% of disabled children live in workless households, compared to 16% of all children.<sup>35</sup>

Parents may also be exposed to new sources of stress over time as their disabled child grows up,<sup>36</sup> related to communication or mobility problems which may impede children's ability to live independently; the extent to which they may be able to integrate into society and receive education; or to parents' concerns about their child's ability to establish a family of their own.<sup>37</sup>

One important source of stress external to the family can be the dealings with statutory agencies. Parents of disabled children have talked in research, for example, about the way in which people outside the family (particularly public services professionals) viewed them primarily as *carers* rather than *parents* – which parents felt had the effect of de-personalising the relationship.<sup>38</sup> Research by the charity Mencap in 2013 found that eight out of ten families with a child with a learning disability said they had reached or nearly reached breaking point as a result of lack of services.<sup>39</sup> Moreover, many parents felt that professionals did not always acknowledge the expertise that they had as parents, and felt they were treated as passive recipients of services.<sup>40</sup>

Difficulties parents and carers face in accessing support can also be exacerbated by the way in which the benefits system identifies needs. Many of the benefits to help parent carers meet the extra costs of having a disabled child are accessed by the child being in receipt of particular benefits, in particular Disability Living Allowance (DLA). If a child under 16 claims DLA, this can then give the carer access to benefits such as Carers Allowance or the Disability Component of Child Tax Credits. But uptake of DLA among young children is low, at just over half of the total number of disabled children under the age of 16 in the UK,<sup>41</sup> and many families with disabled children may be missing out on the additional financial support to which they may be entitled because their child is not in receipt of DLA.

Finally, the additional financial strain many families suffer can in turn impact upon the family relationships. As bringing up disabled children costs more money and takes more time, parents of disabled children are more likely to experience financial difficulties. It is estimated that the annual cost of bringing up a disabled child is three times greater than that of bringing up a non-disabled child,<sup>42</sup> and in the UK 40% of disabled children live in poverty, which equates to around 320,000 disabled children, with almost a third of these classified as living in 'severe poverty'.<sup>43</sup> Research by the Joseph Rowntree Foundation in 2001 found a gap between parents of disabled children's spending and what they said was the minimum necessary to meet their requirements, and that benefits needed to be £28/week higher to bridge this gap.<sup>44</sup> The study also found that the majority of parents of disabled children said they were worried about not having enough money and how they would manage financially.<sup>45</sup> More recent data confirms this picture. The Department for Work and Pensions' *Households Below Average Income* data shows, for example, that on both relative and absolute measures, those living in a family with a disabled family member are more likely to have low income than non-disabled families, and 20% of people in families with a disabled family member lived in relative low income (i.e. below 60% of median income) (before housing costs) in 2014/15 compared to 14% of families with no disability.<sup>46</sup> In Contact a Family's 2011 research, 54% of parents of disabled children said that not having enough money was the cause of their isolation.<sup>47</sup>

It's not only the parental couple relationship that can be impacted by these additional strains of parenting children with a learning disability. Studies also show impacts on wider family relationships. One study found that 30% of parents of disabled children reported that they had lost all contact with friends, relatives, or extended family members.<sup>48</sup> Sometimes other family members were unable to accept the emotional and practical implications of children's conditions and in some families, relationships with grandparents and even partners ended.<sup>49</sup> Even where these relationships were maintained and family members were able to adjust, parents reported that these relationships changed and concluded that it was a 'completely different way of life'.<sup>50</sup> Parenting children with a learning disability can also impact on parents' social participation: research has found that parents of children with a learning disability reported lower rates of social participation than other parents, for example – probably due to the increased financial strain and the more time-consuming care demands.<sup>51</sup>

The intensity of parents' caregiving and of their children's needs may be an important factor in how parents' wellbeing is affected. Research with parents and caregivers of children with cerebral palsy, for example, found that having fewer caregiving demands translated into better physical and psychological wellbeing for caregivers.<sup>52</sup> Studies also point to differences in impacts on parents by disability type. For example, studies indicate that parents of children with autism spectrum disorders are at risk of higher stress levels than parents of children with other developmental disabilities as well as those with typical development.<sup>53</sup>

## What affects our relationships?

Although parents of children with a learning disability may face particularly severe pressures, all parents and indeed all partners have to cope with strains which can cause stress in relationships. Sources of strain such as financial pressure or lack of time are near-universal. The difference is one of degree: with access to the right support there is no reason why parents who have a child with a learning disability should not enjoy the same quality of relationships as other parents.

The quality of relationships depends on a number of things. One of the most widely-cited theoretical models, based on findings from over 100 longitudinal studies (the 'Vulnerability-Stress-Adaptation Model), explains relationship quality in terms of three inter-related factors:<sup>54</sup>

- The personal traits and experiences ('vulnerabilities') partners bring to their relationship – temperament, self-esteem, family background, beliefs and attitudes, etc.;
- External stressors experienced over the course of the relationship – such as economic pressure and poverty, work stress, becoming parents, drug and alcohol abuse, mental ill health, caring for a sick partner, etc.; and
- Adaptive processes – how partners communicate, adapt to change, support each other and cope at stressful times.<sup>55</sup>

The main external stressors which impact on relationships are experienced by parents who have a child with a learning disability and those who do not alike. What is different – as we've seen above – is that families with a child with a learning disability may be at greater risk of experiencing some of these pressures, such as financial strain due to the costs of care and lack of support.

For example, there is plenty of research which shows that financial pressures place a strain on all relationships. Studies find that money worries increase the risk of relationship breakdown, while improvements decrease it.<sup>56</sup> Lower-income households are most likely to experience lower relationship satisfaction<sup>57</sup> and are more likely to have arguments about money – arguments which typically are more pervasive, problematic, recurrent, and remain unresolved than other arguments.<sup>58</sup> Similarly, economic recessions are associated with increased conflict and marital tension,<sup>59</sup> and people who are disadvantaged economically are considerably more likely to experience relationship deterioration and breakdown: Relate’s research into how people’s economic conditions following the 2008-9 ‘Great Recession’ correlated with their relationship experiences found that those who were worst affected during recession were up to eight times as likely to have experienced relationship breakdown.<sup>60</sup> Relate and Relationships Scotland have also previously found that money worries are the biggest strain people report on their relationships: 55% of respondents to *The Way We Are Now* 2015 survey ranked money worries in the top three relationship strains. And those with children were more likely to say this, with 61% of those with children saying money worries were a strain compared to 47% without.<sup>61</sup>

Similarly, pressures which stem from caring are also common to all relationships. Again, our previous *The Way We Are Now* research found that childcare/bringing up children was a principal relationship strain, with nearly a third of parents with a child under five reporting this.<sup>62</sup> A wealth of studies shows that becoming a parent can have a major impact on a couple relationship and it’s one of the biggest challenges that a couple can face, ranking alongside bereavement and moving house as one of the most stressful life events.<sup>63</sup> Unsurprisingly, therefore, becoming a parent is one of the life events most likely to reduce relationship quality and satisfaction.<sup>64</sup> As couples adjust to the demands of providing care for a new baby, evidence shows many experience a concomitant reduction in their relationship quality<sup>65</sup> – in fact it’s estimated that 40-70% of couples experience a decline in relationship quality in their first year of parenthood.<sup>66</sup> Upon becoming parents, partners typically spend significantly less time together and many couples engage in less positive interactions and argue more,<sup>67</sup> which on average leads to a reduction in relationship satisfaction.<sup>68</sup> A summary of 20 years’ research in this field concluded that first-time parents are at increased risk of experiencing personal and marital distress, and that this can continue well after the baby reaches the age of two.<sup>69</sup> Where people have more taxing care responsibilities, this further increases pressure on relationships: research has found that kinship carers (family members, usually grandparents, who step in to look after children when their parents are not able to), for example, experience greater relationship strain.<sup>70</sup>

To recap, extra pressures on the relationships of parents who have a child with a learning disability experience are not simply inevitable corollaries to parenting a child with a learning disability. They’re often the same common stressors we all face from time to time – different in quantity more than quality – which are intensified by a lack of support in the face of extra need. We must be careful not to ‘pathologise’ the condition of parents with a child who has a learning disability who in many cases will be coping as well as other parents, especially where sufficient support is in place.

# Relationships for parents of children with a learning disability

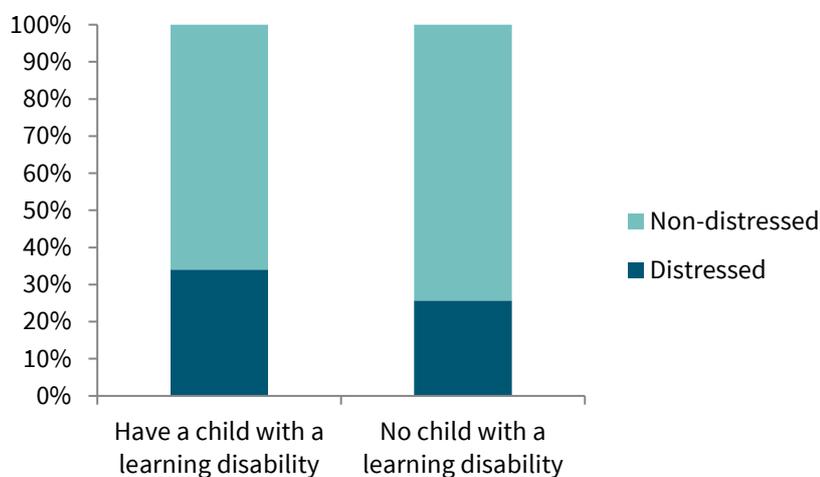
So how are parents of children with a learning disability faring in terms of their relationships today? We now turn to examine our data – beginning with parents’ couple relationships.

## Parents’ couple relationships

### Relationship quality

To measure respondents’ relationship quality we used a scientifically-validated measure called the Couple Satisfaction Index (four-item version),<sup>71</sup> which provides a threshold for distinguishing distressed from non-distressed relationships. In our survey, parents with a child with a learning disability were more likely than parents of children without a learning disability to be experiencing relationship distress, according to this measure. Relationship distress levels for parents with a child with a learning disability were eight percentage points higher than for other parents: **whereas 26% of parents whose children did not have a learning disability scored below the relationship distress threshold** on this validated measure of relationship quality, among **parents with a child with a learning disability this rose to 34%.**

**Figure 1: Relationship distress levels for parents of children with a learning disability and parents of children without a learning disability<sup>1</sup>**



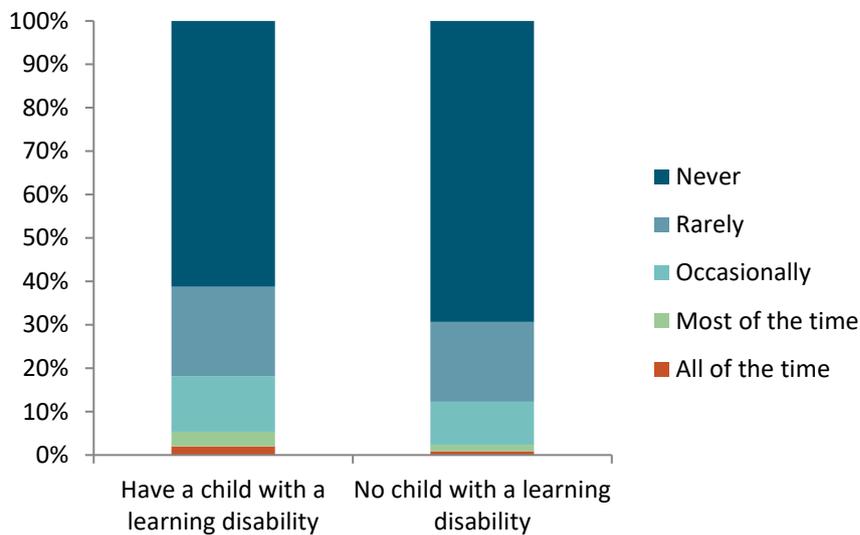
This finding supports the previous studies referred to above which indicate that parenting a child with a learning disability may increase the risk of experiencing relationship distress for the parents. Since experiencing relationship distress is a significant risk factor for

<sup>1</sup> The sample here of parents who reported they had a child with a learning disability and who were in relationships and answered the questions in the questionnaire which form the Couple Satisfaction Index was 150. This means that, while the difference between parents of children with a learning disability and those without *is* statistically significant ( $p < 0.05$ ), the confidence level (i.e. the percentage of all possible samples that can be expected to include the true population parameter) for the proportion of parents of children with a learning disability in distressed relationships is only 78%.

poorer adult mental and physical health as well as poorer outcomes for children, this increased risk of relationship distress for parents of children with a learning disability is concerning. It also highlights a likely need for more targeted support for parents, including relationship support, to strengthen their relationships in the face of the additional challenges they may face, and to build the relational resilience which can help to see them through.

When we looked at responses to additional questions in our questionnaire on respondents' relationship quality besides the brief four-item version of the Couple Satisfaction Index, we found this picture of lower relationship quality among parents of a child with a learning disability was clearly sustained. We found, for example, that **parents with a child with a learning disability were more likely to report at least occasionally considering divorce/separation** than other parents, with 18% of parents of a child with a learning disability reporting this compared to only 12% of parents without a child with a learning disability.

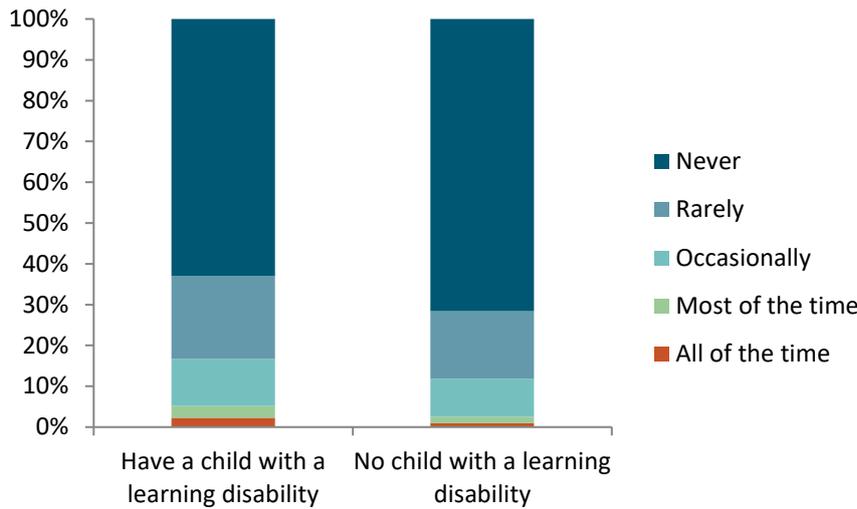
**Figure 2: Frequency with which partners report considering divorce or separation<sup>2</sup>**



Similarly, we observed that parents with a child with a learning disability were more likely to report that they regretted getting married than other parents. As above, among married parents whose children do not have a learning disability, **12% reported that they** at least occasionally **regret getting married**, whereas **17% of married parents who had a child with a learning disability said they regret getting married** at least occasionally.

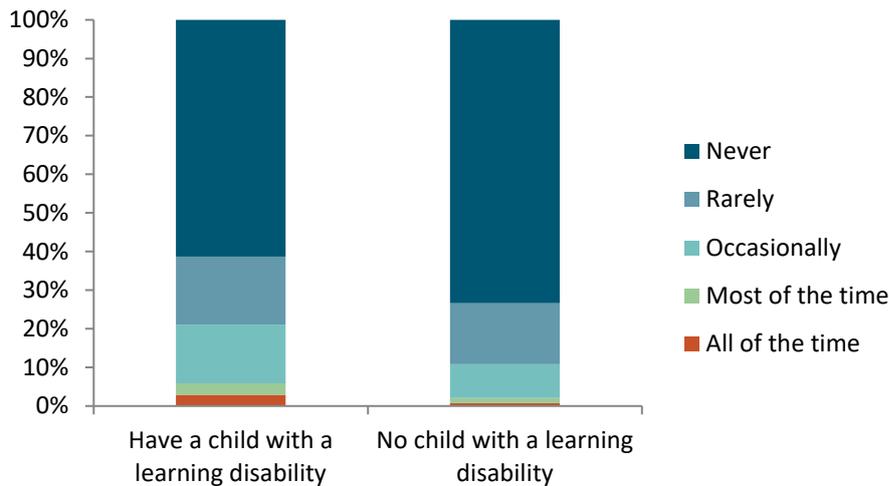
<sup>2</sup> Sample size for parents of children with a learning disability: n = 204. While the difference between parents with children with a learning disability and those without is statistically significant (p<0.05), the confidence level for results for parents of children with a learning disability is 84%.

**Figure 3: Frequency with which partners report regretting getting married<sup>3</sup>**



The difference was more stark when we asked cohabiting respondents about the frequency with which they regretted living together. **Parents with a child with a learning disability were almost twice as likely as other parents to report at least occasionally regretting living together than other parents (21% compared to 11%).**

**Figure 4: Frequency with which partners regret living together<sup>4</sup>**

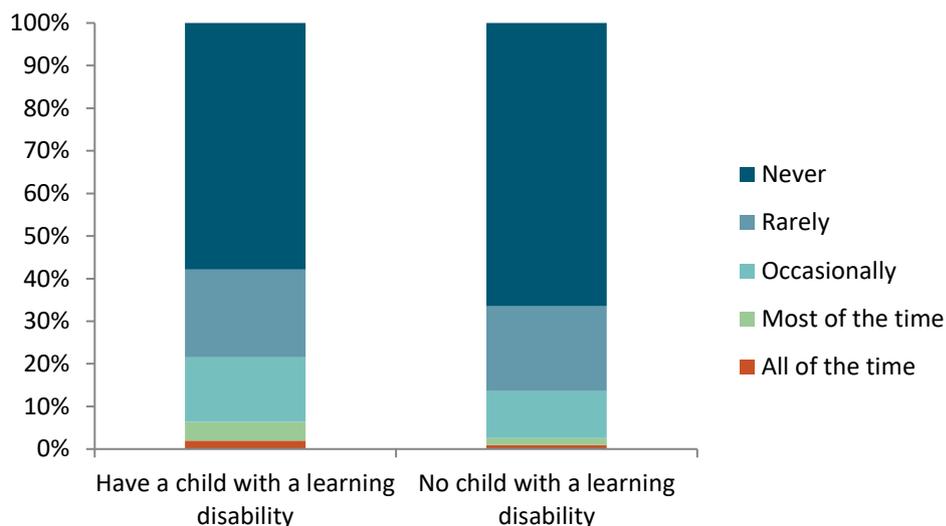


Unsurprisingly, in view of these findings, we also observed that **parents with a child with a learning disability** who were in relationships were **more likely to report** at least occasionally **regretting being in the relationships than other parents: 22% of parents with a child with a learning disability reported this, compared to 14% of other parents.**

<sup>3</sup> As previous, for parents of children with a learning disability n = 173; confidence level: 81%

<sup>4</sup> For parents of children with a learning disability, n = 204; confidence level: 84%

**Figure 5: Frequency with which partners regret being in their relationship<sup>5</sup>**



We saw earlier, when reviewing previous research literature, that a common finding across many studies looking at the impact of parenting a disabled child was the strain on parents’ time. This is something common to almost all parents, of course – but children with a learning disability may have more intensive care requirements and complex needs, particularly if their disability is profound, and as a result parents may face particularly acute pressures on their time.

We asked respondents about the frequency with which they are able to find some dedicated time to spend together as a couple – for example, for ‘date nights’. We found that **parents of a child with a learning disability were more likely (41% more likely) than other parents to only have dedicated time to spend together as a couple (e.g. ‘date nights’) only once a year or less.** Nearly a quarter (24%) of parents who have a child with a learning disability only find time for this once a year or less, compared to less than a fifth (17%) of other parents.

**Table 1: Frequency with which partners spend time together as a couple**

How often do you and your partner find dedicated time to spend together?	Have a child with a learning disability <sup>6</sup>	No child with a learning disability
Never	13.64%	11.75%
Less than once a year	7.27%	4.03%
Once a year	3.18%	1.65%
A few times a year	19.55%	23.59%
Once a month	12.27%	11.03%
Once a fortnight	9.55%	5.64%
Once a week	11.36%	12.52%
More than once a week	23.18%	29.78%

<sup>5</sup> n = 204 parents of children with a learning disability; confidence level: 84%

<sup>6</sup> n = 220; confidence level: 86%

And at the other end of the spectrum, where parents are able to find time for date nights together more than once a week, fewer than a quarter of parents of children with a disability were able to do this compared to three in ten parents of children without a learning disability.

Our counterpart survey of 300 relationship support practitioners, which we undertook alongside the nationally representative survey, provided another angle from which to see the way in which parents with a child with a learning disability may experience particular strains on their relationship: **57% of the counsellors surveyed reported that, over the past year, they had counselled clients where parenting a child with an identified or suspected learning disability had led to strain on their couple relationship.**

## Relationship strains

We also asked respondents about the things which cause or have caused strains on their current or past relationships, asking respondents to select up to eight strains out of a possible 23 listed, or to write their own. We observed some telling differences here between parents of children with a learning disability and parents who did not have a child with a learning disability. For example, while ‘money worries’ was the most-selected option identified by both groups, there was a clear difference between the groups in how much it was identified as a strain, with parents with a child with a learning disability more likely to identify money worries as a strain on their relationships. Whereas **29% of parents without a child with a learning disability said that money worries caused strain on their relationships, among parents with a child with a learning disability this rose to 39%**. This confirms the picture we saw earlier from wider research showing that parenting a disabled child is associated with a higher risk of experiencing financial difficulty and poverty.

A second significant difference in terms of how parents identified strains on their relationships was observed in the extent to which parents said that childcare/bringing up children caused strain on their relationships. Among parents of children without a learning disability, 12% identified this as a strain, but almost one in five (18%) parents of children with a learning disability said this was a source of strain on their relationships.

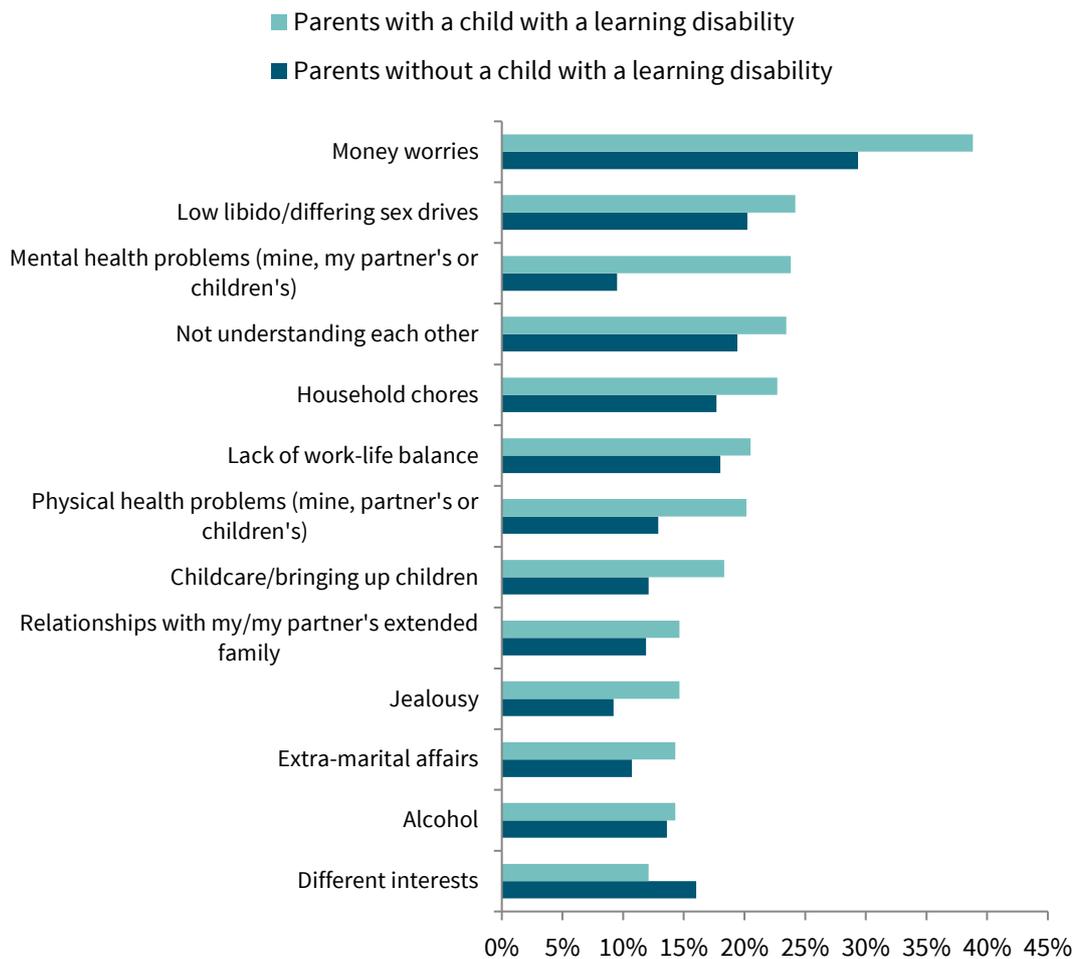
The most significant differences were observed in relation to physical and mental health problems. **Parents of a child with a learning disability were more than twice as likely to say that mental health problems caused strain on their relationships:** while fewer than 10% of parents without a child with a learning disability said that mental health problems (including their own, their partner’s, or their children’s) were a strain on their relationships, almost a quarter (24%) of parents with a child with a learning disability said mental health problems caused strain on their relationships. While this was not among the top 10 relationship strains identified for parents of children without a learning disability, it was the second biggest strain for parents of children with a learning disability.

For physical health problems (again, including respondents’ own, their partner’s or their children’s), while the difference was not quite as stark as for mental health, we nonetheless observed the second biggest difference. **Parents of children with a learning disability were considerably (more than 50%) more likely to identify physical health problems as a strain on their relationships,** with a fifth (20%) identifying this as a strain compared to 13% of parents without a child with a learning disability.

The figure below presents the top (i.e. most-selected) 14 strains (where more than 10% of

respondents chose this in at least one group).

**Figure 6: Relationship strains<sup>7</sup>**



### Attitudes to relationships and relationship support

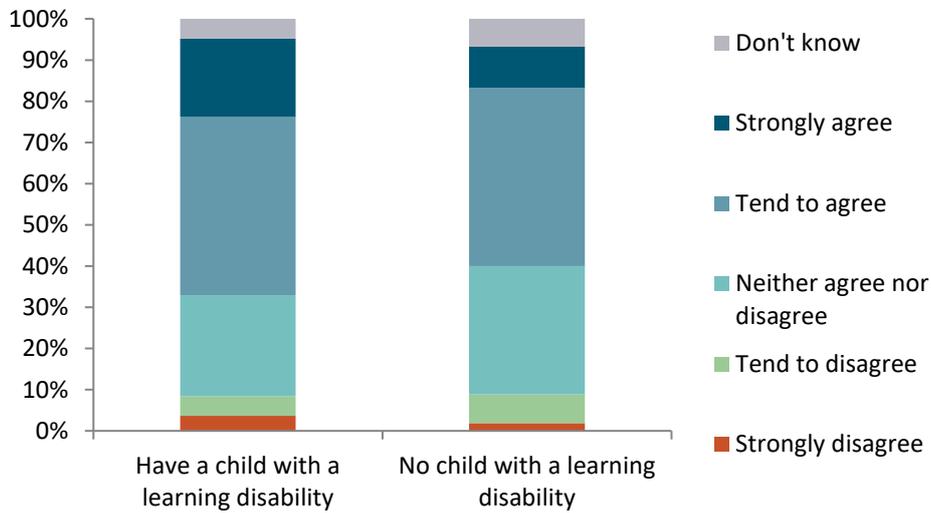
We also looked at whether or not attitudes towards relationships and relationship support varied between these parents. Given the additional strains on the relationships of parents of children with a learning disability, evidenced in our survey as well as wider research, there is good reason to target extra support towards these parents.

When we asked respondents the extent to which they agreed or disagreed with the statement ‘All relationships come under pressure from time to time, and everyone could benefit from support with their relationships’, we found that although all parents were more likely to agree than disagree, whereas 53% of parents without a child with a learning disability agreed, 64% of parents with a child with a learning disability agreed. This may suggest that parents of children with a learning disability are less fatalistic about relationships and more open to a ‘developmental’ model of relationships, according to which relationships change over time and partners can put ‘work’ in to make their relationships stronger and overcome challenges together – and where, therefore, relationship support can be seen to be beneficial. A study by OnePlusOne found that people with more ‘developmental’ perspectives were more likely to be motivated to

<sup>7</sup> n = 273 parents of children with a learning disability; confidence level: 90%

maintain and improve their relationships, including seeking out relationship support, than were those who were more fatalistic and conceived of themselves more passively, with low sense of agency, did not perceive much change or conflict, and did not invest heavily in work to strengthen their relationships.<sup>72</sup>

**Figure 7: ‘All relationships come under pressure from time to time, and everyone could benefit from support with their relationships’<sup>8</sup>**



<sup>8</sup> Among parents of children with a learning disability n = 273; confidence level: 90%

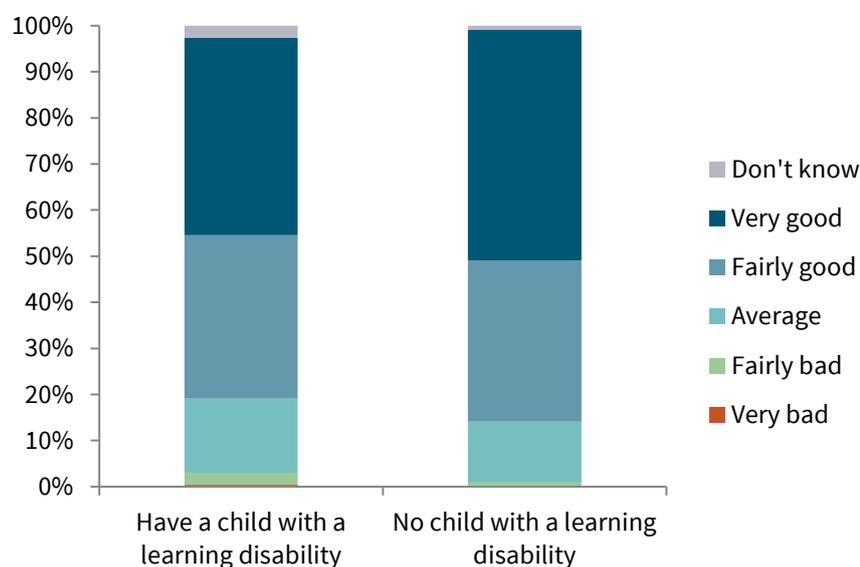
## Social relationships

In addition to looking at parents' couple relationships and any impacts here of parenting a child with a learning disability, we examined parents' social relationships. Wider social networks are also important assets for everyone – but perhaps particularly so for parents of disabled children to prevent isolation, given the additional pressures they may face. When we face times of stress and strain, turning to friends and social networks for support, empathy, sharing experiences, and for comfort through difficult times can be vital for maintaining our wellbeing. When we're isolated, our health suffers. Studies show, for example, that on average people with strong relationships are 50% more likely to survive life-threatening illness than people with weaker ones.<sup>73</sup> And research also shows that for families with disabled children, support from friends can provide an important buttress which sustains families' ability to cope.<sup>74</sup>

But just as with family relationships, previous studies have indicated that families with disabled children may have reduced contact with social networks due to the demands of caring for children with intensive needs on their time and money. Research in 2011 found that 65% of families with disabled children in the UK said they felt isolated frequently or most of the time.<sup>75</sup>

In our survey, parents with a child with a learning disability reported less good quality relationships with friends than other parents. **While 85% of parents without a child with a learning disability reported good relationships with their friends, 78% of parents with a child with a learning disability reported good relationships.**

**Figure 8: Relationships with friends<sup>9</sup>**



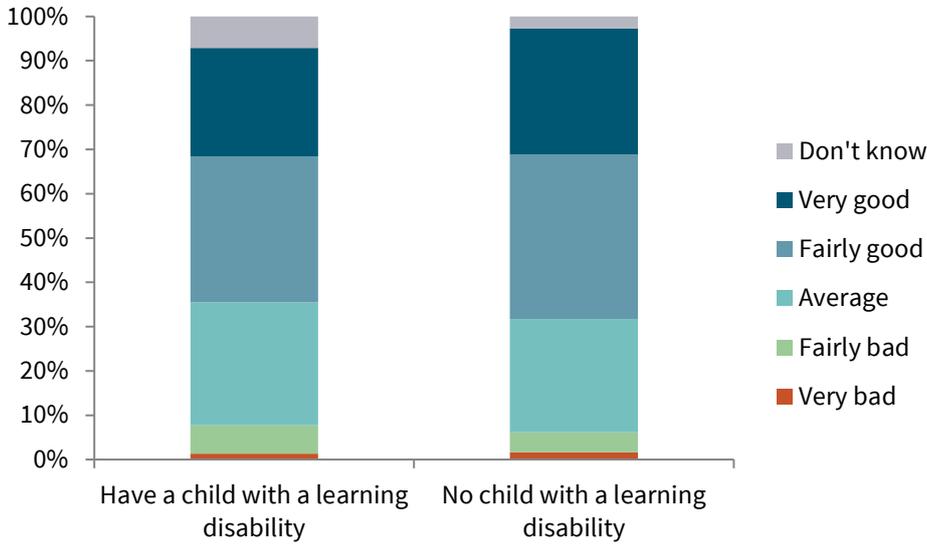
More worryingly, however, we found that almost **one in six (17%) parents with a child with a learning disability said they have no close friends**. When we asked this question of the whole sample in last year's *The Way We Are Now*, we found that across the sample as a whole, one in ten people had no close friends.<sup>76</sup> It therefore appears that parents of a child with a learning disability are 70% more likely than the population as a whole to not

<sup>9</sup> n = 260 parents of children with a learning disability; confidence level: 89%

have a single close friend.

We also asked respondents about the quality of their relationships with their neighbours, and found that, again, there was a small difference here. **Parents with a child with a learning disability were less likely to report good relationships with their neighbours: 62% reported good relationships, compared to 66% of parents without a child with a learning disability.**

**Figure 9: Relationships with neighbours<sup>10</sup>**



<sup>10</sup> n = 256 parents of children with a learning disability; confidence level: 89%

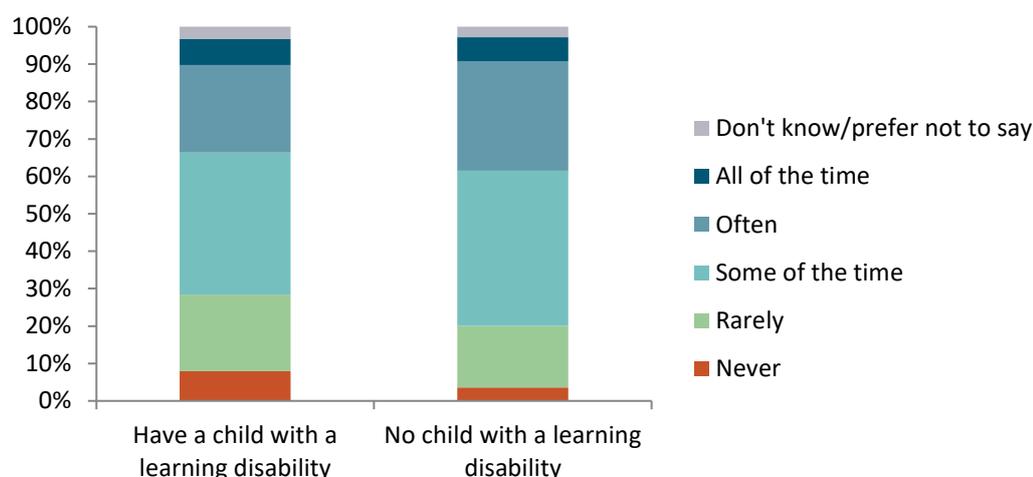
## Parents' wellbeing

Given the well-evidenced contribution of personal and social relationships to our wellbeing (as we saw earlier), we also looked at some indicators of parents' wellbeing to see if we could identify any overall apparent impact on parents' wellbeing of the above inequalities we observed in terms of parents' relationships with each other and with social networks.

We might expect families who have a child with a learning disability to experience lower levels of wellbeing – and we saw above, of course, previous research which found 72% of families with disabled children experienced mental ill health such as anxiety, depression or breakdown and almost half had felt so unwell that they had asked their GP for medication or had seen a counsellor, due to their isolation.<sup>77</sup> A meta-analysis of a number of other studies similarly found mothers of children with developmental disabilities to be at an elevated risk of depression compared to mothers of typically developing children.<sup>78</sup>

Our data showed that parents of children with a learning disability in our sample were less likely to feel good about themselves, and were **40% more likely to never/rarely feel good about themselves** than parents without a child with a learning disability: 28% said they felt good about themselves rarely or never, compared to 20% of parents with a child with a learning disability. And eight per cent of parents with a child with a learning disability said they never feel good about themselves.

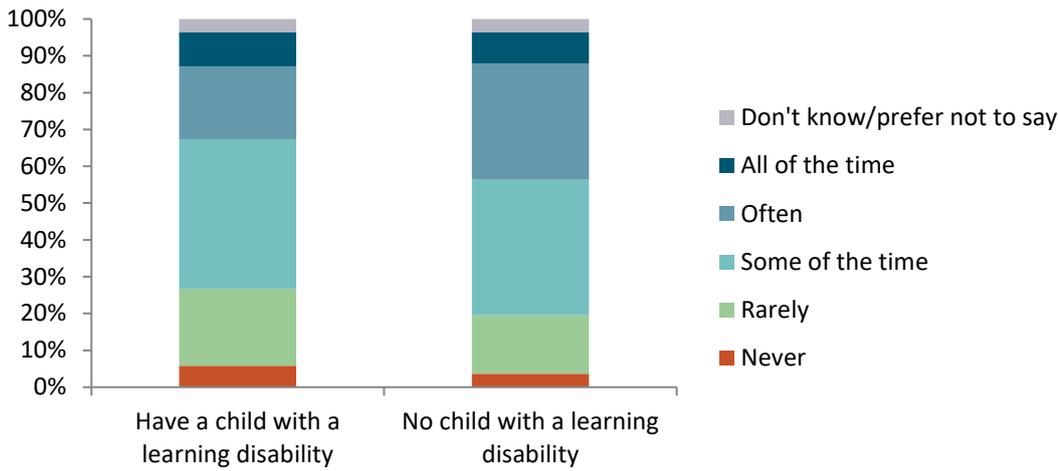
**Figure 10: How often parents feel good about themselves<sup>11</sup>**



Similarly, parents of a child with a learning disability were also less likely than other parents to feel optimistic about the future: these parents were 37% more likely to say they never/rarely feel optimistic about the future, with **over a quarter (27%) of parents of a child with a learning disability saying they never or rarely feel optimistic, compared to less than a fifth (19%) of other parents**. And whereas 40% of parents without a child with a learning disability said they felt optimistic all the time or often, only 29% of parents of children with a learning disability did so.

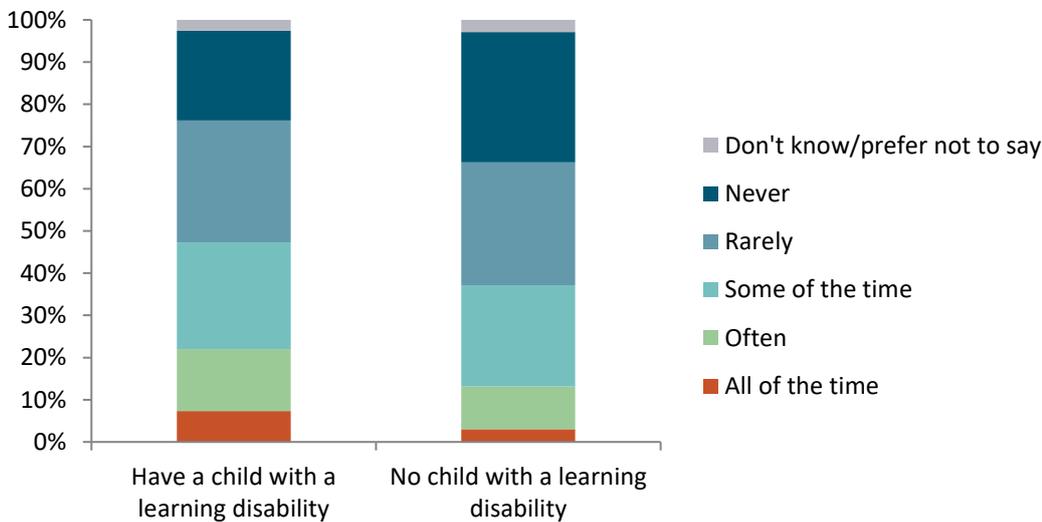
<sup>11</sup> n = 273 parents of children with a learning disability; confidence level: 90%

**Figure 11: Feelings of optimism**<sup>12</sup>



We noted earlier the previous research finding that parents of disabled children may be more prone to isolation as a result of their intensive caring responsibilities. Our survey similarly found that parents of children who have disabilities were more likely to report loneliness or not feeling close to others. In our survey, parents with a child with a learning disability were more likely to feel lonely: whereas 60% of other parents reported that they felt lonely never or rarely, for parents of children who have a learning disability this was 10 percentage points lower, at only half (50%). And **over a fifth (22%) of parents of a child with a learning disability said they felt lonely often/all the time** – almost 70% higher than the 13% of other parents who said this.

**Figure 12: How often parents feel lonely**<sup>13</sup>

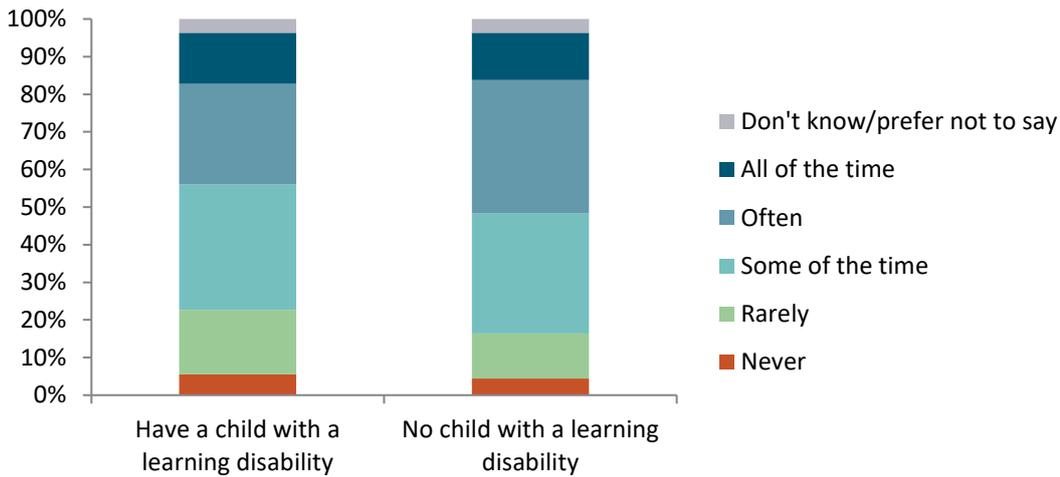


These parents were also less likely to feel close to others. **Almost a quarter (23%) of parents with a child with a learning disability said that they never or rarely felt close to others, compared to 16% of other parents.**

<sup>12</sup> n = 273 parents of children with a learning disability; confidence level: 90%

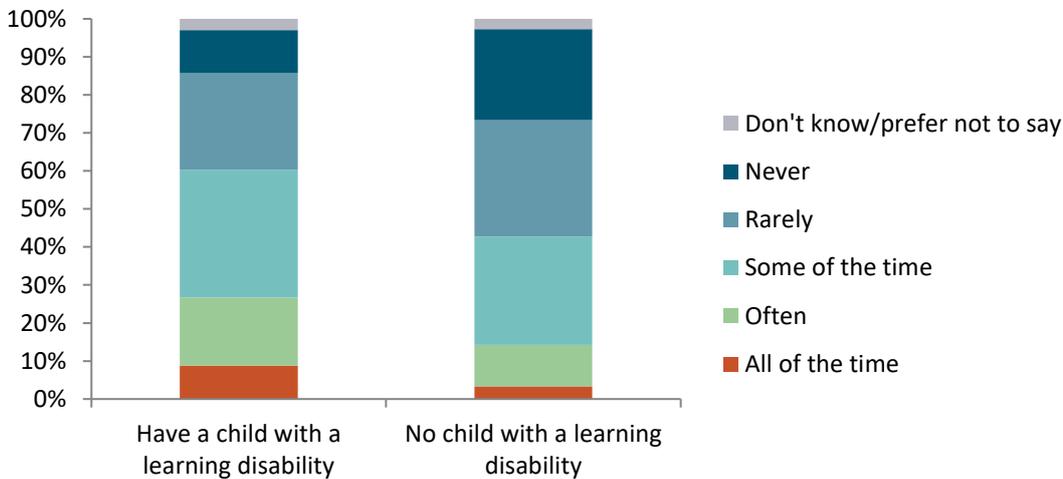
<sup>13</sup> n = 273; confidence level: 90%

**Figure 13: Feeling close to others<sup>14</sup>**



And finally, alarmingly, parents of children with a learning disability in our sample were considerably more likely to report feeling down, depressed or hopeless. **Parents of children who have a learning disability were almost twice as likely to say that they felt down, depressed or hopeless at least often: over a quarter (27%) of parents with a child with a learning disability said they felt down/depressed/hopeless often or all the time, compared to only 14% of other parents.** Nine per cent said they feel down, depressed or hopeless all the time. And almost half of parents without a child with a learning disability said they never or rarely felt this way, compared to only 37% of parents of children.

**Figure 14: Feeling down/depressed/hopeless<sup>15</sup>**



This stark difference in parents’ wellbeing would appear to indicate a significant level of unmet need for further support for these families – in terms of mental health support to deal with the emotional consequences of providing intense care for a child with a learning disability, for example, or the practical and/or financial support with the day-to-day caring which could prevent this poorer mental wellbeing in the first place – or both.

<sup>14</sup> n = 273 parents of children with a learning disability; confidence level: 90%

<sup>15</sup> n = 273; confidence level: 90%

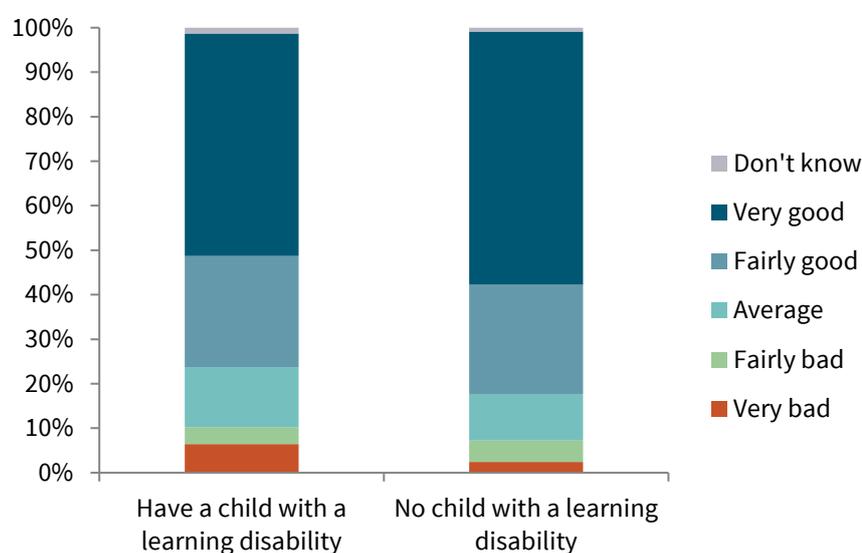
## Family relationships

A supportive family network can be a vital resource which can help families to cope and prevent isolation, particularly for parents whose children have more profound and intensive needs. Research indicates, for example, that the negative impacts on parents' wellbeing which are associated with parenting a disabled child are reduced when parents receive greater support from their families.<sup>79</sup> We therefore also looked at the quality of other family relationships for parents of children with and without a learning disability.

However, as we saw earlier, previous studies have found that parents of disabled children may experience greater strain on their family relationships, including losing contact with them,<sup>80</sup> and seeing their relationships deteriorate if other family members are unable to accept the emotional and practical implications of caring for a disabled child.<sup>81</sup> One qualitative study found that parents of disabled children reported that relationships and roles had to be re-negotiated, in terms of emotional aspects and practical tasks, and concluded that it was a 'completely different way of life'.<sup>82</sup>

While most parents across our sample enjoyed good relationships with their mum and dad, we did observe a slight difference here, with parents with a child with a learning disability reporting lower quality family relationships than parents without a child with a learning disability. Parents with a child with a learning disability were less likely to report a good relationship with their mum: **three-quarters (75%) of parents with a child with a learning disability rated their relationship with their mum as 'good', whereas more than eight in ten (81%) of parents without a child with a learning disability did so.**

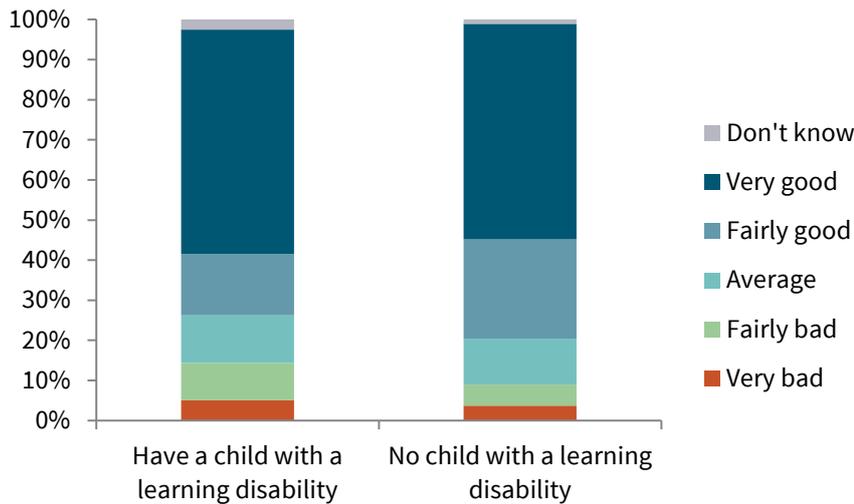
**Figure 15: Relationships with mum<sup>16</sup>**



Similarly, we observed a difference regarding the quality of parents' relationships with their dad: parents with a child with a learning disability reported lower levels of good relationships: **71% said these relationships were good, compared to 78% of parents without a child with a learning disability.**

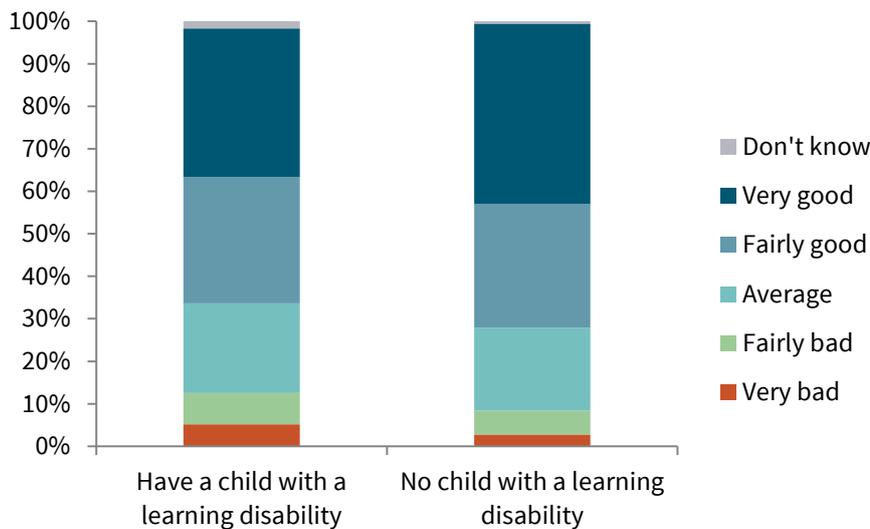
<sup>16</sup> Among parents of children with a learning disability n = 156; confidence level: 79%

**Figure 16: Relationships with dad<sup>17</sup>**



A similar pattern held for relationships with siblings: the proportion of parents with a child with a learning disability who reported good relationships with their siblings was seven percentage points lower than that for parents without children with a learning disability: **72% of parents without a child with a learning disability reported good relationships, whereas only 65% of parents with a child with a learning disability did so.**

**Figure 17: Relationships with siblings<sup>18</sup>**

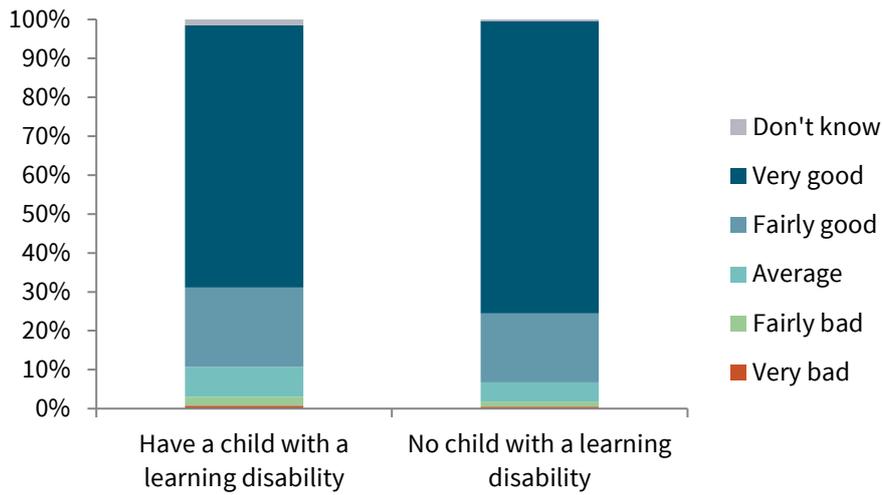


Finally, we also observed a difference – smaller, yet still significant – in terms of parents’ reported relationships with their children (which of course included the child/ren with a learning disability, but could also include other children if they had any). **While 88% of parents with a child with a learning disability reported good relationships with their children, for parents without a child with a learning disability this was 93%.**

<sup>17</sup> n = 118 parents of children with a learning disability; confidence level: 72%

<sup>18</sup> n = 232; confidence level: 87%

**Figure 18: Relationships with children<sup>19</sup>**



It is not possible to determine whether these differences in intra-familial relationships are due to experiences of parenting a child with a learning disability or whether they are rather down to the fact that families of children with a learning disability are more likely to experience stress factors which affect these relationships than are families without children with a learning disability.

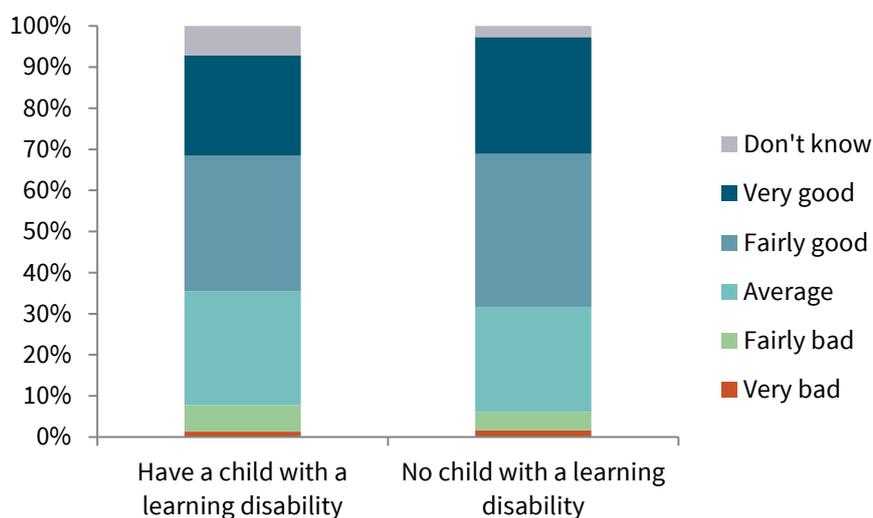
<sup>19</sup> n = 260 parents of children with a learning disability; confidence level: 89%

## Work

Previous research has tended to look at the impact on work of parenting disabled children in terms of isolation and a reduced ability to work; one survey found that 57% of families with disabled children said their isolation as carers meant they were not able to work as much as they would like.<sup>83</sup> It has examined how parents can be forced by the demands of caring to give up work, reduce hours, and forgo careers and promotion opportunities.<sup>84</sup>

In our survey, we wanted rather to understand the quality of the relationships surrounding parents. So we asked respondents about their relationships at work (with bosses and colleagues) to see whether parenting a disabled child was associated with any difference here. Where parents of disabled children may need to leave work or reduce hours due to the demands of caring, or request flexible work arrangements to aid the balancing of work and family/care, for example, a good relationship with their boss may be particularly important. Sadly, however, in our survey, **parents with a child with a learning disability reported lower quality relationships with their boss than other parents, with 57% and 66% respectively reporting good relationships with their boss.**

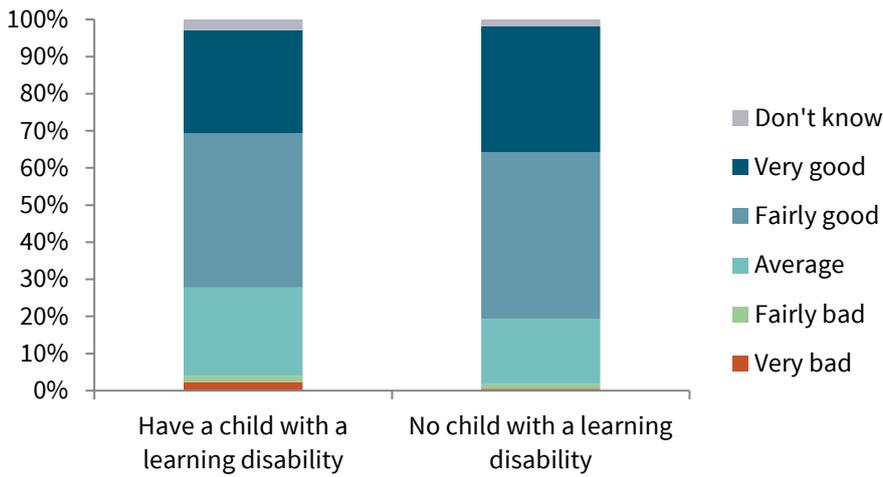
**Figure 19: Relationships with bosses<sup>20</sup>**



We found some good news in that relationships with work colleagues were of good quality for all parents. Yet we also found a clear difference here (starker than for relationships with bosses) between the two categories of parents: **the proportion of parents with a child with a learning disability who reported good relationships with colleagues was 10 percentage points below that for parents of children without a learning disability (69% and 79% respectively).** Given the increased risk of isolation for parents of disabled children, as evidenced in wider research, this difference suggests that some of the parents who may most need good quality work relationships are unfortunately less likely to enjoy them.

<sup>20</sup> n = 155 parents of children with a learning disability; confidence level: 78%

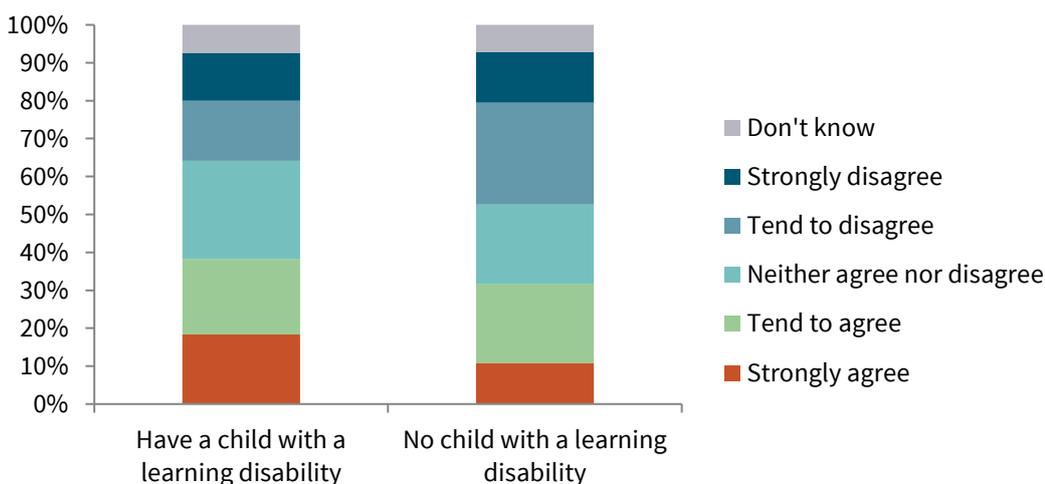
**Figure 20: Relationships with colleagues<sup>21</sup>**



As we saw in our previous *The Way We Are Now* report on relationships at work and the balance of work and family (*Labour of love – or labour versus love?*), the extent to which we’re able to effectively balance work and family life matters for our own wellbeing and also our productivity. When we’re overworked, we’re more likely to become ill, perform less well, and leave our jobs; when we’re satisfied with work and work-life balance, we’re more likely to perform better. Similarly, when we are unable to find a good balance, our relationships also tend to suffer, while in their turn, strained personal relationships can affect our overall health and wellbeing and reduce our work engagement.

Unfortunately, our survey found that parents who have a child with a learning disability feel under greater pressure to put work before family life: **nearly four in ten (38%) parents with a child with a learning disability agreed that their employer thinks work should be the priority in a person’s life, compared to closer to three in ten (32%) of parents without a child with a learning disability.**

**Figure 21: ‘My employer thinks that work should be the primary priority in a person's life’<sup>22</sup>**



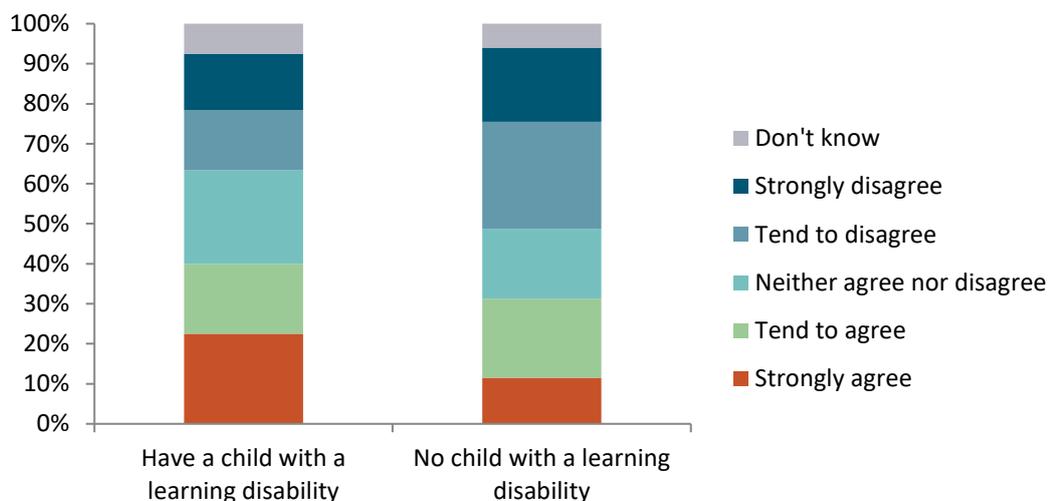
<sup>21</sup> n = 173 parents of children with a learning disability; confidence level: 81%

<sup>22</sup> n = 120; confidence level: 72%

And if we look only at those who strongly agreed with this, 18% of parents with a child with a learning disability strongly agreed – seven percentage points higher than other parents. We may speculate that a potential explanation for this difference might be the additional caring demands these parents face which makes these parents feel this pressure to put their work first most acutely.

Similarly, in our survey **parents with a child with a learning disability were more likely than other parents to agree that their employer’s ideal employee is available 24 hours a day, with 40% agreeing, compared to 31%.** And these parents were more than twice as likely to strongly agree with this, with 23% strongly agreeing, compared to 11% of other parents.

**Figure 22: ‘My employer thinks that the ideal employees are available 24 hours a day’<sup>23</sup>**



<sup>23</sup> n = 120 parents of children with a learning disability; confidence level: 72%

## Dual caring

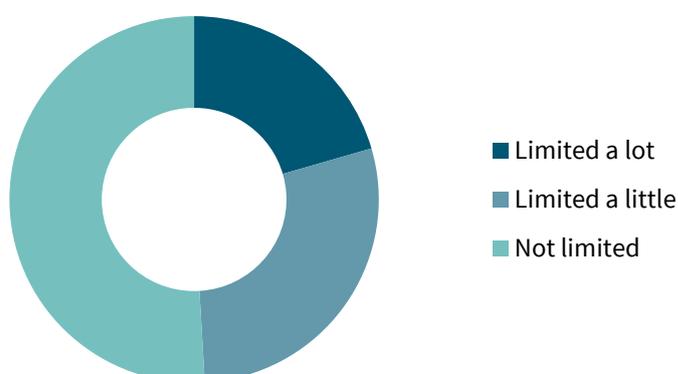
Finally, we examined families' wider caring roles. Besides balancing family life with work, many families are also balancing family life with other caring responsibilities. This is increasingly the case: as the UK population continues to age and the pensionable age continues to rise, and as the costs of social care continue to soar, family members are increasingly taking on care responsibilities. It is estimated that, with our ageing population, the number of people who provide care to older parents (in England) will increase by over 20% from 2007 to 2032 – reaching 485,000.<sup>85</sup> Unpaid care by family members is consequently becoming more and more important.<sup>86</sup> Today it is estimated there are seven million unpaid carers in the UK – and over the next 30 years, the numbers are expected to increase by 3.4 million to over 10 million.<sup>87</sup> Many of these carers provide quite intensive care: between 2001 and 2011 the largest increase in unpaid carers was seen in those who provided fifty or more hours of care per week, and it's estimated that 1.4 million people now provide 50 plus hours of care every week.<sup>88</sup>

Evidence shows that caring responsibilities can have an adverse impact on the physical and mental health of those who care.<sup>89</sup> Carers who provide high levels of care, for example, are more than twice as likely to suffer poor health as people without caring responsibilities,<sup>90</sup> and in the 2013 State of Caring Survey, 84% reported that caring had a negative impact on their health.<sup>91</sup> When combined with the demands of parenting a disabled child, this may amount to very considerable pressures for many parents.

Our findings highlight the likely support needs of many families who are balancing parenting a child with a learning disability with other caring responsibilities. In our sample, **39% of parents with a child with a learning disability reported that they also provided formal or informal care for others (besides their own children).**<sup>24</sup>

And an even higher proportion of parents of a child with a learning disability reported that they themselves were disabled or limited by a long term condition. **Almost half (49%) of parents with a child with a learning disability in our survey also reported that they were themselves limited by a disability or long term condition.**

**Figure 23: Proportion of parents of a child with a learning disability who are also themselves disabled or limited by a long term condition<sup>25</sup>**



<sup>24</sup> n = 273 parents of children with a learning disability; confidence level: 90%

<sup>25</sup> n = 273; confidence level: 90%

# Recommendations

Given the importance of relationships and the particular challenges families who have a child with a learning disability may face, policy-makers can make a significant impact in supporting families. And it is reasonable to suppose that doing so will not only significantly improve families' wellbeing but also reap wider benefits for society and the taxpayer through reducing the costs associated with responding to relationship distress.

What can policy-makers do to support these families? In response to these research findings, Relate and Mencap have jointly identified a number of key policy recommendations which would reduce the stressors on relationships which can be particularly acute for families with a child with a learning disability and therefore help to prevent relationship difficulties, and improve the way in which services respond to relationship difficulties which are caused by these pressures.

## **1. Good quality information for parents on what support is available**

Clear and easily accessible information is key to ensuring that parents of children with a learning disability are aware of the support that is already available to them in their local area. Local authorities in England are under a duty to provide a Local Offer that sets out the support they expect to be available in their area for children and young people with special educational needs and disabilities (SEND), which includes children with a learning disability. However, there is currently no duty to ensure that this local offer comprehensively sets out the local support that is available to parent carers of children with SEND. This denies them the opportunity to easily access information that could help to address issues that might affect their wellbeing. In addition, this removes the opportunity for local areas to monitor and review the sufficiency of their local provision for carers in their area and, subsequently, to fill any gaps in provision, where necessary.

## **2. Effective identification and assessment of parents and family carers of people with a learning disability**

The findings in this report offer a stark message that parents of children with a learning disability are not getting the support they require to reduce the increased pressures they face and to ensure that they can maintain positive relationships. The report also shows that there is a clear need to prioritise additional support for families of children with a learning disability as there are increased stress factors on them and their intra-familial relationships.

Local authorities are currently under a duty to assess parent carers on the appearance of need in order to determine whether they have needs for support and, if so, what those needs are. However, there is a clear need for identification of family carers of children with a learning disability to happen earlier and more effectively and for assessments and any identified support to be put in place earlier.

## **3. Increased take up of 'passporting' benefits for parent carers and disabled children**

As we noted earlier, many of the benefits that seek to help parent carers meet the extra costs of having a disabled child are accessed by the child being in receipt of certain benefits, in particular Disability Living Allowance (DLA) which exists to help address the

additional costs associated with having a disability. If a child under the age of 16 claims DLA, this can entitle a carer access to benefits such as Carers Allowance or the Disability Component of Child Tax Credits, for example.

However, uptake of DLA amongst young children in particular is worryingly low: official DWP figures show that there are just 53,470 claimants of the care component of DLA for children aged 0-5, 188,790 for children aged 5-11, and 174,420 for 11-16 year olds.<sup>92</sup> These figures combined represent just over half of the total number of disabled children under the age of 16 in the UK.<sup>93</sup> This means that there is a risk that many families of disabled children are unable to access the additional financial support they might require to reduce pressures on them that might cause negative wellbeing.

If the government continues to use DLA as a proxy for identifying disabled children, it must be sure that all children who are eligible for it are able to claim it, thus allowing families to access the additional financial support they might require.

#### **4. Short breaks for parents**

Short breaks or respite care means time off for family carers, via short break centres, short-term placements with other families, or direct payments to purchase support. Such short breaks or respite care can be important to allow parents the break they need from what can be intensive caring demands – but can also have benefits for children with a learning disability, as this can also involve specialist care.

As we saw earlier, Mencap's 2013 research on the provision of respite services for family carers revealed that eight out of ten parents and carers had reached breaking point – gone beyond their emotional, psychological and physical limits – as a result of not getting the support they need, including a lack of short breaks.<sup>94</sup> Short breaks are therefore essential to help ensure families have good mental and physical wellbeing, as well as enabling them to spend quality time together. However, Every Disabled Child Matters also found that a majority (58%) of local authorities cut spending on short breaks between 2011/12 and 2015/16 and only 9% of parents who responded to an EDCM survey agreed or strongly agreed that families with disabled children can access the short breaks they need.<sup>95</sup>

There is currently a duty on local authorities to provide a range of short breaks that enable family carers to continue caring for a disabled child. However, recent evidence shows many families are not receiving the short breaks they need. Ensuring there is adequate funding for short breaks provision is therefore required to guard against any further reduction in this service for families of children with a learning disability. In fact, there is a need for additional services that can meet needs more proactively than is currently the case; before families reach breaking point.

#### **5. Better childcare support for families of children with a learning disability**

This research has identified a number of pressures on families of children with a learning disability that result from issues around childcare. Almost one in five parents of children with a learning disability said childcare was a strain on their relationship and our findings regarding balancing work and family also indicate significant issues with maintaining healthy relationships at work. Access to affordable childcare that can meet a child's additional needs can therefore help to reduce pressures on families of children with a learning disability.

However, the Independent Inquiry into Childcare for Disabled Children found that 66% of families pay more for childcare for their disabled child than non-disabled child.<sup>96</sup> Furthermore, a report by Mencap, Contact a Family, the Family and Childcare Trust and Council for Disabled Children found that 40% of parents of disabled children don't access their full free entitlement to 15 hours of free childcare per week over 38 weeks of the year and 25% of these families said their child was refused a place at, or excluded from, a nursery because of their additional needs.<sup>97</sup>

Local areas and childcare providers need to ensure equality of access to childcare for children with a learning disability that is predicated on adequate funding, suitably-trained staff and effective local special educational needs and disabilities support. The government recently confirmed its plans to allocate additional funds to local authorities for disabled children (again, based on those who claim DLA), as well as requiring local areas to establish a SEN Inclusion Fund. However, to be successful, this must be approached strategically, to ensure that all disabled children, including children with a learning disability, are assisted to access all early years settings and, consequently, it is important that an action plan is produced by each local area to specifically look at this issue from the perspective of disabled children.

#### **6. Targeted relationship support for parents of disabled children and children with a learning disability**

Finally, given the extra pressure our data suggests parents with children with a learning disability may experience on their relationships, policy makers and commissioners should expand access to relationship support with particular focus on targeting support for people with a learning disability and their families. Local authorities should ensure that relationship support for parents is included within the menu of support options available locally in the Local Offer. Central government should also ensure that families who have a child with a learning disability are explicitly included within government's identified target groups of people most at risk of relationship difficulties and/or distress within the forthcoming social justice strategy, and that funding for relationship support, which was doubled over this parliament, expands access for families where a family member has a learning disability.

# Methodology

The survey was carried out by YouGov Plc using an online interview survey administered to members of the YouGov UK panel of over 800,000 individuals who have agreed to take part in surveys. An email was sent to panellists selected at random from the base sample according to the sample definition, inviting them to take part in the survey and providing a link to the survey. YouGov normally achieves a response rate of around between 35% and 50% to surveys although this does vary according to the subject matter, complexity and length of the questionnaire.

In total we polled 5,071 UK adults (over 16) across England, Wales, Scotland, and Northern Ireland. Fieldwork was undertaken between 18<sup>th</sup> June and 7<sup>th</sup> July 2016. The figures have been weighted and are representative of all UK adults (aged 16+). YouGov is a member of the British Polling Council. All figures, unless otherwise stated, are from YouGov Plc.

The results of our poll were weighted to make the data more representative of the population in terms of age, gender, region and country, and an indicator of social class (based on census information). However, the results do come with some caveats around representativeness. While the results of our survey are weighted according to these criteria, our sample may still differ according to other unobserved factors, including those that are the subject of our survey, such as relationships and sexual behaviour. It should be noted that we do not know how representative our sub-sample of people who have children with a learning disability was of people across the UK who have a child with a learning disability.

Additionally, we were not able to compare the characteristics of the sample of parents who have a child with a learning disability with the wider sample in terms of income, education, child age, etc. and other factors which may play a role. We therefore assume for purposes of analysis that the characteristics of the two groups are similar, but there could be unknown differences in these background characteristics which may account for some of the differences in terms of relationships.

Respondents were identified as having a child (of any age) with a learning disability or not, according to responses to the following question, based on Mencap's definition of learning disability:

*A learning disability is a reduced intellectual ability and difficulty with everyday activities – for example household tasks, socialising or managing money – which affects someone for their whole life. Thinking about this, do any of your children have a (recognised or suspected) learning disability?*

Out of our sample of 5,071, a total of 3,115 respondents said they had children (of any age), and of these, nine per cent (280) said in response to the question above that they had a child (of any age) with a recognised or suspected learning disability. Thus, while our overall sample was more than 5,000, our sub-sample of people with children with a learning disability was only 280.

These data were further analysed independently of YouGov on behalf of Relate using STATA 13 with individual weights attached to all sample members; direct replication of the statistics featured in this report using the tables published by YouGov may therefore be subject to rounding errors. Additional variables, such as relationship status, which

were not available in the standard output provided by YouGov, were subsequently created and feature throughout the report. All of the bivariate analyses that we present represent statistically significant patterns and differences – these are patterns that we would not expect to see by chance.

However, the small sample size (which shrinks yet further when we cross-break how respondents' answers to the definition question compare with their answers to other questions) means that our results come with important caveats. Not only are we uncertain how representative our sample of parents of children with a learning disability is of the wider population of families with children with a learning disability, but the confidence level (i.e. the percentage of all possible samples that can be expected to include the true population parameter) for our results is significantly lower than the 95% confidence level we operate at throughout the rest of our *The Way We Are Now* research reports.

## Definitions of terms

Throughout this report, the following terms are used in the description of findings:

**'Child with a learning disability'** – we used a definition of learning disability provided by Mencap: "A learning disability is a reduced intellectual ability and difficulty with everyday activities – for example household tasks, socialising or managing money – which affects someone for their whole life." We asked parents whether any of their children (any age) had a recognised or suspected learning disability.

**'Relationship distress'** – A 'distressed' relationship is one with a severe level of relationship problems, which has a clinically significant negative impact on partner's wellbeing. Research shows clear links between relationship distress and depression, anxiety, increased blood pressure and heightened risk of heart attacks, for example.

**'Good'** – including those who responded 'very good' and 'fairly good'

**'Bad'** – including those who responded 'very bad' and 'fairly bad'

**'Agree'** – including those who responded 'strongly agree' and 'tend to agree'

**'Disagree'** – including those who responded 'strongly disagree' and 'tend to disagree'

**'At least some of the time'** – including those who responded 'some of the time', 'often', or 'all of the time'

**'At least occasionally'** – including those who responded 'occasionally', 'most of the time', or 'all of the time'

**'People who are disabled or living with a long term health condition'** – including people who reported that their day-to-day activities are limited because of a health problem or disability which has lasted or is expected to last at least 12 months.

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This report forms the third of a series of reports which together comprise our major study into the state of the UK's relationships, *The Way We Are Now*.

## About Relate

Relate is the UK's leading relationship support organisation, serving more than one million people through information, support and counselling every year. Our vision is a future in which healthy relationships are actively promoted as the basis of a thriving society.

We aim to develop and support healthy relationships by:

- Delivering inclusive, high quality services that are relevant at every stage of life
- Helping couples, families and individuals to make relationships work better
- Helping both the public and policy makers improve their understanding of relationships and what makes them flourish.

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## About Relationships Scotland

Relationships Scotland supports a network of 22 member services across Scotland. We support family relationships, especially at times of crisis and key family transitions. We provide face-to-face support to over 15,000 people each year.

Our work focuses on prevention, early intervention and child protection. We provide relationship counselling, family mediation, child contact centres and other related forms of family support across all of Scotland.

Around 1,000 people are actively involved in the delivery of our services across Scotland, including around 600 volunteers.

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## About Mencap

Mencap supports the 1.4 million people with a learning disability in the UK and their families and carers. Mencap fights to change laws and improve services and access to education, employment and leisure facilities, supporting thousands of people with a learning disability to live their lives the way they want.

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