



Better conversations about

Supporting employees with a disabled child

When an employee has a disabled child, what do employers and those working with them need to know so that better conversations at work can take place?

Jane Moffett shares what can help



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How many of your employees have a disabled child and what impact do you think this has on their lives – including their life at work? It's worth asking yourself this question, as, with over 750,000¹ children having some kind of disability, it's important to consider the myriad experiences, needs and emotions that the parents of these children have. If circumstances are particularly difficult, the different reality is very much at the forefront of an employee's mind as the daily experiences of this group of parents can be so demanding. But how much is it present in the thinking of colleagues, managers and HR departments?

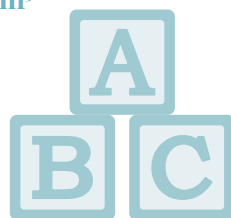
Money

From a purely financial perspective, having a disabled child costs families approximately £580 to £1,000 more per month.² These added costs are due to a variety of reasons; for example, specialist toys and play

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provision, holiday insurance, parking for hospital appointments and treatments, and therapies, such as speech and language therapy, hydrotherapy and physiotherapy, many of which need to be paid for privately as free access to these is dependent on what is available locally. One parent I talked to spoke of the fact that specialists indicated that her child needed certain services to help with his developmental delay, but the services actually available to her could not respond to these needs; this appears to be a common theme. For employees returning to work, the already expensive childcare options are further inflated if you have a disabled child; the cost of a nanny specialising in special educational needs could be as much as £60,000 per annum.³

Emotional cost

The financial implications are only a small part of the picture, though.

Having an understanding of other things that can impact parents is vital. Firstly, there is the emotional rollercoaster that comes with being the parent of a disabled child, which was highlighted in a recent survey of parents conducted by Affinity Hub, an organisation that offers emotional support to parents of children with special needs.⁴ While there are very real positives that range from enjoyment of and pride in your child, to developing a much deeper understanding of yourself, harnessing determination, gaining other perspectives (and new friends) and building hope and a sense of purpose, there are also negative emotions. These might include feeling anxious, stressed, helpless, frustrated, angry, confused and having a fear of the future; a mother I spoke to recently said that she was in a permanent state of: 'carrying the stress that he's not normal'. Good quality support from family and friends was highlighted as necessary.

New mums

Becoming a mother for the first time – whatever the situation – is a major life transition, which can affect a woman's self-identity and wellbeing, as

discussed in an earlier article I wrote for *BACP Workplace*, 'When mothers return to work'.⁵ At the point of returning to work, as well as concerns for revalidating herself at work and reinforcing her 'viable employee identity', many parent returners also struggle with leaving their baby to be cared for by someone else. The fear, guilt and concern that many women experience at this time can be even greater if they are leaving a disabled child in childcare, as was highlighted to me recently by a counsellor who works with parents of disabled children. She commented on the high degree of stress that is felt on the return to work, around whether or not their child with extra needs will be cared for well enough. For counsellors supporting working parents of a disabled child, acknowledging this increased stress can be important.

Support and communication

As in so many situations, support is key. When this type of support is also offered at work, it is recognised and appreciated. This is an important point, which is highlighted clearly by Claire, in a case study on the Working Families website:

'My employer was really understanding and accommodating. Our family weathered that storm and things settled down again. If my employer had been hostile, I might have left.'⁶

She works full time and is the mother of a child with autism and learning difficulties and explains that because of the extra demands that come with having a disabled child, going to work can provide a haven, as long as employers are, 'patient and supportive'. She explains: 'I knew I wanted to keep working – and felt determined to do so.' She describes the workplace as, 'a sane environment ...which can be a lifeline for me.'

Conversely, many parents find that work is affected by their situation. As the Affinity Hub report findings show: 'The negative effect on work was noted and several parents had either given up work, or had to adapt it to care demands, including too many appointments, their own health and not being able to juggle both.'⁴

Flexibility and sensitivity

This juxtaposition between the benefits of being in a workplace and the difficulty of maintaining a job is important to note. At a time when being at work can provide a lifeline, the stress of needing to take time off to attend the many appointments that are typical for disabled children can put a strain on relationships and expectations at work. While employees are entitled to unpaid parental leave for emergencies, in blocks of a day (rather than a week for parents of children who are not disabled), there is no legal right to time off to accompany a child to an appointment.⁷ However, it might well be that an employer has policies in place that go over and above the minimum required by law. As a manager, knowing these policies and being able to point employees in the right direction can help reduce anxiety.

As well as being up to speed on policies, regularly having proactive conversations with parent employees who have disabled children can be of

Practical tips for parent employees⁴

- Give yourself time. It gets easier
- Ask for and seek help
- Be confident dealing with services and trust your instinct
- Enjoy and appreciate your child
- Find good quality friends who 'get' your life
- Find emotional support
- Look after yourself. Take it day by day. Be strong
- Don't hide away.

benefit. Saying, 'Let us know what you need' is a start – but only a start. For many members of staff in this situation, they don't want to be singled out as being different and don't want to be discriminated against; it is also very difficult for most people to ask for help. However, things are different and more challenging, so having regular meetings where managers check up on how people are and ask them how they can best support them in their caring role, is a big positive step forward.

Share best practice

This step forward is not just one-way – learning more about their experiences can help to develop your organisation's policies around supporting parents with a disabled child. Also, your employee will have developed more efficient and effective ways of working so that they can be a good employee and a good parent of a child with additional needs. What can you, as a manager/organisation, learn that can be filtered through to the rest of your workforce – both with regards to other parent employees who have a child with a disability, and to your workforce in general?

Another common outcome of having a disabled child is the impact on

careers. Taking the plunge to move from an organisation that is known to be supportive, to one that is unknown, can be too much of a deterrent. Reflecting on her experience working, Claire says: 'There have been times I've put off applying for more senior roles. I'm nervous about leaving an understanding and supportive manager and going into unknown territory. So, having Ariella – particularly with her special needs – has definitely affected my life and career – even though I've been lucky enough to keep working.'⁶

It could be that people are staying with a supportive organisation because they don't want to take the risk of moving to a new employer who might be less supportive. This doesn't mean that they're not interested in career advancement, though, so employers need to provide opportunities for promotion, recognising what an amazing job their employee is doing by still being performing well at work while also having a harder job to do at home than many other parents in their workplace.

As with many other situations that are unexpected, don't shy away from the issue – be proactive, initiate conversations and remember to ask the employee what support would make the most difference to them. ●

REFERENCES

- 1 <http://www.disabilitysport.org.uk/facts-and-figures-about-disabled-people-in-the-uk.html> (accessed 4 November 2019).
- 2 <https://www.scope.org.uk/news-and-stories/life-costs-more-for-disabled-children-and-their-families/> (accessed 22 October 2019).
- 3 https://www.workingfamilies.org.uk/wnd_mandy_swaran/ (accessed 22 October 2019).
- 4 <https://www.affinityhub.uk/userfiles/documents/Report%20of%20findings.pdf> (accessed 4 November 2019).
- 5 Moffett J. Better Conversations about: when mothers return to work. *BACP Workplace*, 2018; 98: 14–19.
- 6 https://www.workingfamilies.org.uk/wnd_claire_ariella/ (accessed 22 October 2019).
- 7 <https://www.workingfamilies.org.uk/articles/time-off-work/> (accessed 4 November 2019).



RESOURCES

Working Families

www.workingfamilies.org.uk
Helpline: 0300 012 0312
advice@workingfamilies.org.uk
The helpline is for parents and their advisers and gives advice on employment rights for parents and benefits for families. The helpline is run by a team of solicitors and advisors and has an Advice Quality Standard Quality Mark.

Affinity Hub

Emotional support for parents of children with special needs
www.affinityhub.uk
A report into the emotional impact of parenting a child by Joanna Griffin, Chartered Counselling Psychologist – Affinity Hub UK.
<https://www.affinityhub.uk/userfiles/documents/Report%20of%20findings.pdf>

Advice for managers and employers supporting parent employees

- Arrange meetings once or twice a year with parent employees who have a disabled child to ask how things are and what they need.
- Recognise that the start of the working day might not be the start of the day for your employee – they might already have had a long morning/night.
- Try to ask them if they would like a cup of tea, rather than commenting on their time-keeping.
- Remember that holidays are not always a 'break'.
- When organising social occasions, ensure that there is a mix of evening and daytime events, as it may be difficult to find an appropriate baby-sitter.
- Avoid generalisations about common life stages: it can be painful if assumptions are made that all children of a certain age will learn to drive, go to university, leave home or get married.
- Provide opportunities for promotion; having a disabled child doesn't mean that employees are not interested in their career advancement.

If you have thoughts about any of the issues raised in 'Better conversations about...' or have an idea for an article of your own, we would like to hear from you. Please email the editor: workplaceditor@bacp.co.uk