

# **Scottish Parliament Social Justice & Social Security Committee**

## **Inquiry into Addressing Child Poverty through Parental Employment**

### **Submission by Children's Hospices Across Scotland (CHAS) – 02 June 2023**

#### **Overview**

For over thirty years, families across Scotland caring for a child with a life-shortening condition have been able to turn to CHAS for world-class emotional, practical and medical support. This care begins from the point a child's condition is diagnosed or recognised, and extends right the way through to either bereavement or transition to adult services.

The latest research shows that there are over 16,700 children live with a life-shortening or potentially life-shortening condition in Scotland, and that number is rising<sup>1</sup>. Many of these young people may currently be stable, and not approaching end of life.

We know that many of families we support struggle financially. Children with a life-shortening condition are 50% more likely to be living in the most deprived parts of Scotland compared with the least deprived.

Over 45% of the children we supported in 2022/23 were from the two most deprived quintiles in Scotland, and there is significant regional variation within that figure. For example, 73% of the families we support in the Glasgow region come from the most deprived quintiles, compared with only 23% in the Highlands and Islands region (Regions refer to Scottish Parliamentary regions).

And life with a child with complex medical needs can result in additional expenses – such as specialist equipment, adaptations, and higher energy bills – at a time when family members are often less able to work due to their caring responsibilities.

“Having a disabled child costs so much more than having an able-bodied child, just to do simple things. It costs much more just to clothe my daughter - repeatedly - than it would if she didn't have her condition, as well as life being so much more difficult in general. Having financial stress on top of that is an added burden we don't need” – Parent

The families we support experience a wide variety of different circumstances. While some of the children and young people we support are stable enough to attend a

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<sup>1</sup> Children in Scotland requiring Palliative Care (ChiSP) 3, CHAS / Public Health Scotland. Sept 2020

school or childcare setting on a regular basis, not all are. And while some parents manage to balance work with caring needs, not all can.

It is worth noting that while for some parents, work is a part of their identity, sense of self-worth and purpose, not all parents get a choice. The barriers to re/entering the workforce while balancing the responsibilities of being a parent of a child with complex health needs – and often other children too - are very real.

## **The importance of access to childcare for children with complex needs**

Access to high-quality, affordable and accessible childcare is important for the educational and social development of seriously ill and disabled children. Through effective childcare, children with complex needs are able to see progress in both their physical and mental well-being. However, there is general recognition that these services are in decline due to funding restrictions.

The benefits of childcare for seriously ill children include:

- an opportunity to learn by observing and interacting with other children of similar ages
- time and support to build relationships with other children
- chances to practice social skills in real-world situations
- exposure to a wider variety of challenging activities
- an opportunity to learn at their own pace in a supportive environment
- a chance to build relationships with caring adults other than parents.<sup>2</sup>

There are also benefits for parents to having the right childcare in place. It allows them the chance to manage some of the wide range of other tasks associated with their child's care (see more below) or return to work which may give them a sense of identity, purpose, and adult stimulation and company – as well as greater financial stability.

Yet a 2021 UK-wide report by disability charity Contact has found that 87% of mothers with disabled children could not work as much as they would like to, often due to a lack of suitable childcare<sup>3</sup>. We believe it would be reasonable to suggest that that number may be even higher in the case of children with complex health needs.

## **Barriers to employment – the magnitude of the caring role**

“There is no break, no lie-ins, no lunch, can't stop for a cup of tea, most days I just fight to get up, to have the will to carry on through another day.” (Parent)

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<sup>2</sup> <https://www.togetherforshortlives.org.uk/changing-lives/speaking-up-for-children/policy-advocacy/access-to-high-quality-childcare/>

<sup>3</sup> <https://contact.org.uk/wp-content/uploads/2021/11/Counting-the-Costs-2021.pdf>

Few of the families we support are in a position to have two working parents, irrespective of whether their child attends a school or childcare setting for some of the week, and irrespective of whether or not both parents might prefer to be in paid work.

For many of the families we support, one parent is the stay at home carer for their child, often as the second carer in a package of care where a child requires 2:1 support. This parent, often a mum, will be providing hands-on care for their child, 24/7. This will include playing and providing sensory input; supporting their health needs, for example by suctioning their airways, or administering their medication; supporting them with everyday tasks such as bathing and toileting; and attending to the household tasks generated by having a seriously ill child, including a large amount of laundry.

The parent-carer role also includes a significant amount of project management. Even if a child does attend a school or childcare setting, parents will often use that time to catch up on the multitude of other tasks involved in caring for a seriously ill child. This can include chasing up medical appointments for their child; organising OT, physio, play therapy etc; organising any paid carers' rotas; picking up their child's medication; as well as attending to other household matters.

And of course, because the children in question have highly complex health needs, the parent carer will very often get called to take their child home from a childcare or school setting if taken unwell.

We also often find that even where the other parent may be working, the working parent also has to cut back on working hours, or taken on lower paid but more flexible work – especially if the family has more than one child. Research carried out into the experiences of fathers of children with life-shortening conditions reinforces this point. Many fathers who took part in this study revealed how they had to reduce their hours, and in some cases completely stop working to support their wife or partner in providing care to their child, resulting in a reduction or loss of income.<sup>4</sup>

This causes significant stress. One parent told us: “looking after a sick child is stressful enough without worrying about money”.

We also support many single-parent families, for whom combining their caring responsibilities with work is even less feasible.

It is therefore important to acknowledge that for some families, childcare is not the sole barrier into employment. It can simply be the case that for a particular family's circumstances, there is no genuine, feasible choice but for one – or sometimes both parents - to be 24/7 carers.

## **Barriers to employment – lack of social care support**

Parents and carers of children with life-shortening conditions often have to learn complex new skills and procedures in order to care for their child – frequently

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<sup>4</sup> *Exploring Fathers' experiences of living with a child who has a life shortening condition: A Phenomenological approach*, Nicky Bridges, CHAS, 2019

providing round the clock care. This can be socially isolating, stressful, and exhausting.

The quality of the social care support they receive is therefore critically important to the wellbeing of parents and carers, as well as children.

Yet over two-thirds of the families we asked told CHAS there are gaps in their care.<sup>5</sup> There are many contributing factors and differing experiences, however, many families reported that: assessments take too long to happen; that once a package is in place, it does not provide them with the right level of skilled support - such as carers capable of assisting with equipment or checking medications; or simply that staff shortages make recruitment of any support impossible.

## **Case Study – Family in Midlothian**

We support a mum in Midlothian, whose 4 year old daughter has full body cerebral palsy, in combination with a range of other severe health issues. She attends a Local Authority early years nursery 9am-12.30pm, four mornings a week where she receives fully-funded, 1:1 care. She is entitled to more hours, but would not be physically robust enough to do more time at nursery at this stage.

Prior to having her daughter, the mum worked as a clinical support worker in the NHS. She is now a full-time carer for her child. Mum told us:

“Although she’s the only child there with complex medical needs, the nursery have done really well with [my daughter]. She loves it there, and they’re great with her.

“Now that she’s settled in nursery, I’m dying to go back to work for my own mental health. I have nothing that’s mine any more.

“But I can’t plan work shifts because it’s so unpredictable with my wee girl. You think you’re having a good week [with your child], then everything changes with her health”.

“If I get called by nursery to take my wee girl home because she’s unwell, which happens all the time, there’s only me that can do that. I have no-one else to help. My mum doesn’t feel confident in looking after [my child’s needs] if I’m not there. What I really need is appropriate, qualified social care support, to look after her if I’m at work. But I haven’t even had a formal assessment of our needs.”

This experience echoes a situation that many of the families CHAS supports find themselves in. CHAS would like to see children with complex needs assessed quickly for Self-Directed Support, and for decisions about social care entitlements to be focussed primarily on quality and outcomes for the child and family, recognising this may require additional support to recruit and retain highly skilled care assistants.

## **Barriers to employment – financial disincentives to work**

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<sup>5</sup> Survey conducted by CHAS September 2020. The survey received 67 responses.

We would also like to highlight that the social security system can at times act as a disincentive for parents who are unpaid carers to meaningfully enter the workforce. Of particular urgency, the earnings limit for Carers Allowance needs to be reviewed. Carers Allowance has no taper, so carers going over their earnings limit of £139 per week – even by a pound - will lose all of their entitlement to Carer’s Allowance. A carer can therefore only work 13.5 hours at the National Living Wage before they lose their carers allowance entitlement. That is really unfair and it puts a carer’s ability to work at risk.

We echo the call from Carers Scotland that, as Carers Allowance merges with the carer support payment, this is addressed as a matter of priority. Instead of there being a cliff edge, we support a tapering system so that people can work more hours to increase their income.<sup>6</sup>

## **Barriers to employment – lack of suitable, specialist childcare options**

It is important to recognise how specialist and intensive the support required by the children we support is. Many of the children we support need 1:1 or even 2:1 care. They have health needs that require specialist training. They may be on ventilation or oxygen. They may be PEG fed.

We know there are pockets of excellent practice in local authority-run nurseries, and in special schools. And when it works well, that provision makes a huge difference to the families concerned.

One parent told us:

“The nursery has been absolutely brilliant, they are continuing to regularly train, learn and always try to improve. They are giving an amazing experience to our daughter... [T]hey know how difficult it is so we feel really safe and supported.”

Unfortunately, however, the reality is that provision isn’t uniformly available when and where it is needed.

One parent based in Midlothian told us:

“Our government and local authority need to realise that there is near no nursery who have directly the space and the training to take on our wee stars, there is near no after school clubs options, there is near no sports/music/arts activities for our wee super stars. We can’t drop them for an hour, we have very limited options.”

Shared Care Scotland's report – "Holidays or Isolation?" - published in 2020 found that disabled children and young people faced significant isolation from their peers during the holiday period. The research also found that, when available, holiday activity provision exerted a disproportionately powerful positive impact on the lives of

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<sup>6</sup> <https://www.carersuk.org/media/yswdcjur/state-of-caring-2022-a-snapshot-of-unpaid-caring-in-scotland-final.pdf>

disabled children and their families and a disproportionately negative one when it was not accessible to them.<sup>7</sup>

This also applies to the families we support. Holiday and wraparound provision in particular is not readily available for children with complex healthcare needs. Rural communities are likely to be particularly poorly served, due to accessible transport difficulties, but even in major cities – as outlined by the case study in Dundee below – parents may find that the options available to them are very restricted, and do not enable them to work pout of term-time and school hours.

## Case study – Family in Dundee

We support a family in Dundee, who have 7 year old twins, one of whom has an undiagnosed genetic condition with many complications. She is non-verbal and non-mobile. This child currently attends a special school in Dundee, and has previously attended other childcare settings since the age of 9 months. Her mum works in the public sector.

“I’ve been so lucky to have employers who have had family-friendly carer’s policies. I’ve consistently had to take chunks of time off to look after [my child]. But they’ve trusted me. When my wee girl has been unwell, they’ve not hassled me to get back to work, they trust me to come to them when I’m ready and able to return.

“They’ve also let me work flexibly. When I need to take time out to attend medical appointments, or get her wheelchair re-fitted, I’ve not been asked to use flexi-time or annual leave. I’ve been trusted to make up the work when I am able.

“It’s so important to feel like you *can* take time off when you need to, and it won’t be held against you. My husband’s work, in the private sector, is very different.

“We’ve also been really lucky with the childcare settings that have been available for [my child] – though I know of other families who live more rurally who have not been as lucky, so I think it’s a bit of a postcode lottery.

“When she was younger, she attended an NHS nursery in the hospital.<sup>8</sup> There was a nurse on staff at all times, who could administer her medication. And she could get all her physio, speech and language and OT on-site. It was great.

“What we’re really struggling with now that she’s at school though is wraparound care, in the afternoons after school finishes and during the holidays. There are some activities in the holidays, but they’re parent-accompanied. And as our little girl is getting bigger, it’s harder for grandparents to help out. She really needs specialist support.

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<sup>7</sup> [https://yourviews.parliament.scot/sjssc/child-poverty-parental-employment/consultation/view\\_respondent?show\\_all\\_questions=0&q\\_\\_text=&sort=excerpt&order=ascending&uuld=178555480](https://yourviews.parliament.scot/sjssc/child-poverty-parental-employment/consultation/view_respondent?show_all_questions=0&q__text=&sort=excerpt&order=ascending&uuld=178555480)

<sup>8</sup> Armistead Nursery, based at Armistead Child Development Centre within Kings Cross Hospital and operated by NHS Tayside.

“At the moment, my husband and I are really having to juggle our time off to make things work”.

We welcome that the Scottish Government has recently committed £4.5 million for after school and holiday clubs, with a particular focus on the six priority family types identified in the Tackling Child Poverty Delivery Plan, including families with a disabled child.<sup>9</sup>

We would urge the Scottish Government to work in partnership with Local Authorities to ensure that there are more options for specialist, accessible holiday and after school playschemes for children with complex needs.

## **Barriers to employment – after a caring role has ended**

We would also like to highlight that following the death of a child, better support is needed for the whole family, to ensure that bereaved families are not suffering financially or practically, as well as emotionally.

Because while the UK Government which will not impose a ‘work search requirement’ on someone whose child has died for six months after a bereavement, their financial support ends much sooner.

Currently, after a child dies the family will lose Child Benefit, Carers Allowance, the Scottish Child Payment, and Tax Credits within 8 weeks of the child’s death – although the Scottish Government has committed to increasing the duration of Carers Allowance to 12 weeks after a death.

CHAS supports calls by Reform Scotland, Sue Ryder and Marie Curie, to give bereaved carers in Scotland more time than this.<sup>10</sup>

We do not believe that it is realistic, either from an emotional or practical perspective, to expect a bereaved parent - who has often been their child’s carer for many years - to re-enter employment within 3 months. We believe a 6 month grace period with continuation of all the financial support they were previously entitled to would be more appropriate. <sup>7</sup> With the situation as it is, many families who have other children will find themselves struggling financially as they try to manage their grief, and attempt to re-enter employment.

And for those parents who have been in a caring role for many years, re-entering employment may be difficult to achieve. For some, they may feel going into care work is their only option due to their skill-set. But this has the potential to be re-traumatising.

Is it therefore incredibly important that employability services are equipped to be attuned to the specific needs of carers in re-entering the workforce, and are able to

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<sup>9</sup> <https://www.gov.scot/news/increasing-childcare-in-disadvantaged-areas/>

<sup>10</sup> Life After Death: supporting carers after bereavement, Sue Ryder, Marie Curie and Reform Scotland, July 2020

support them with identifying the many transferable skills they have gained during their time as a carer, and how they might be applied in other roles.

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