

BARRIERS TO SHORT BREAKS

Experiences of parent-carers and disabled children and young people in Gloucestershire.

August 2023

What we did

Introduction

In 2022, Barnwood Trust conducted research about the experiences of parent-carers, and disabled children and young people in accessing short breaks and respite care in Gloucestershire. In addition, the Trust spoke to several providers of these services to contextualise what families were telling us. This Executive Summary contains the key findings from the research.

If you would like to know more about this research, please contact Dan Jacques on **01242 539935** or at dan.jacques@barnwoodtrust.org

A note on terminology

The terms **short breaks** and **respite care** are used differently by children's and adult social care services. However, both are used to describe care services providing specialist care and support to families of disabled children and adults so that:

- Unpaid carers receive breaks from their caring responsibilities to maintain their resilience, and their physical and emotional wellbeing.
- Disabled children, young people and adults have opportunities to socialise independently in an environment that is safe, secure and suitable for their needs.

Whereas non-disabled children may be able to complete activities independently or spend time socialising with their friends; for many disabled people this is not possible without the correct environmental adjustments. Such adjustments might include somewhere with specialist facilities such as a hoist, a sensory room, or the provision of specially trained staff who understand the child's needs, behaviours and health conditions. This means that many parent-carers of disabled children require

specialist provision to get the breaks other parents might have.

Such activities could also include many of the childcare activities accessed by non-disabled children such as sports clubs, Brownies, Scouts and drama clubs but with the additional support of a personal assistant (PA), for example.

Who we spoke to

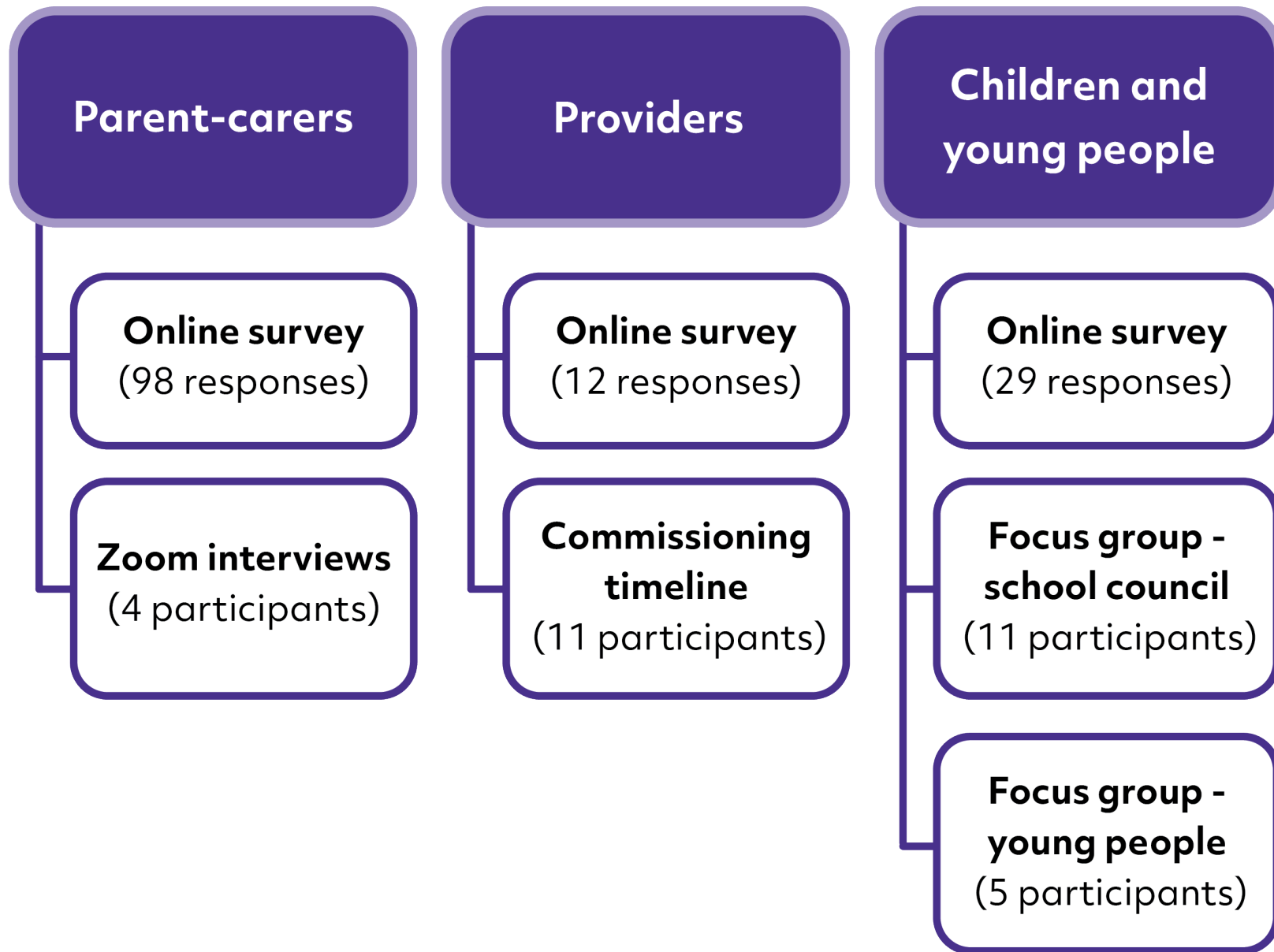
As far as possible, the focus of the research was informed by people with experience of providing, accessing or supporting others to access short breaks and respite care in Gloucestershire. In addition, the research design was informed by an extensive review of literature related to short breaks and respite care in the county.

In total, the experiences of 98 parent-carers, 29 disabled children and young people and 12 participants from local short breaks and respite care providers were captured via surveys. The data gathered through these surveys was built upon through four interviews with parent-carers, a focus group with nine local providers (attended by 11 participants), and two focus groups with disabled young people. One of these focus groups took place at a

local special school and the other was with young school leavers aged between 20 and 25 years old.

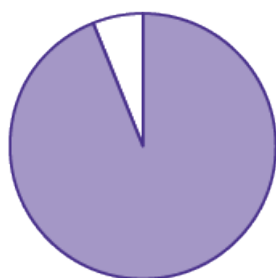
All the research with young people was co-designed with a young Expert by Lived Experience (EbLE). The same EbLE co-facilitated the focus group with young school leavers.

All the data was gathered in line with Barnwood Trust's [Research Code of Practice](#). A copy of this can be found on our website.



What did we find out?

The research findings indicated that parent-carers, disabled children and young people in Gloucestershire were experiencing a range of barriers and challenges to accessing short breaks and respite care. The results of the survey were:



94% of parent-carers told us that they were not currently accessing all the short breaks they felt they needed.



93% of parent-carers told us that they had experienced at least one barrier to accessing short breaks provision.



52% of disabled children and young people told us that they were not attending groups or activities after school or at the weekend.



49% of parent-carers told us that they were not currently accessing any short breaks or respite care support.



49% of parent-carers told us that a lack of information was a barrier to accessing short breaks.



38% of disabled children and young people told us through the survey that they had never been asked about any aspect of the support they were receiving or wanted to receive.

Overall, the research captured three main barriers that were said to reduce opportunities to access short breaks and respite care:

- Assessment
- Information provision
- Availability and suitability

Assessment

In the survey, 43% of parent-carers said that assessments of eligibility were a barrier to accessing short breaks and respite care.

- The **process** of being assessed for eligibility to commissioned short breaks and respite care services was predominantly mentioned as a barrier for parent-carers. They described it as “confusing”, focused on safeguarding and not taking account of the wider context in which families were living.
- Furthermore, several parent-carers also spoke about their perceptions of the **eligibility criteria** for meeting the threshold for assessed needs that entitled them to access short breaks and respite care support. Many parent-carers also perceived

the criteria for eligibility to be applied inconsistently or in ways that were not fully transparent.

- Several parent-carers also reflected their concerns about how assessments were **conducted** including sharing their fear that they or their parenting would be judged and whether or not the process would be worthwhile.

“Because my daughter has low mobility disability and is a happy child with no aggressive behaviours towards others, she did not meet the criteria. The fact that I, as a carer, am often suicidal and with chronic illness, did nothing to get any respite”

- Parent-carer of a disabled young person

Information provision

All three participating groups commented on a lack of good quality information available on short breaks, exacerbated by difficulties communicating with the local authority.

- Several parent-carers were **unaware** of what short breaks and respite care were, whether they had a right to access them, or how to access them.
- For many of those who did know, **trying to obtain** the information they needed or understanding what they had been told was said to be a challenge that limited their access to these services. This included feeling they had to chase the local authority for answers to questions, and that information that was obtained was of poor quality and confusing.
- For some parent-carers, information that is not easily accessible, proactively given or comprehensible was considered to be an additional pull on their **limited time and energy**.
- Providers of short breaks and respite care services described **breakdowns in communication** with the local authority that caused delays and risked the organisations viability; that challenges accessing information caused uncertainty and that many relied on other providers to stay up-to-date with what was happening.

- Disabled children and young people spoke about the barriers of information and communication from a different perspective. Like parent-carers and providers, this group reflected on the lack of information they received about what was available to them. However, many also reported how they had **not had the opportunity to communicate their needs or preferences** – especially to professionals and providers – as they were rarely or never asked.

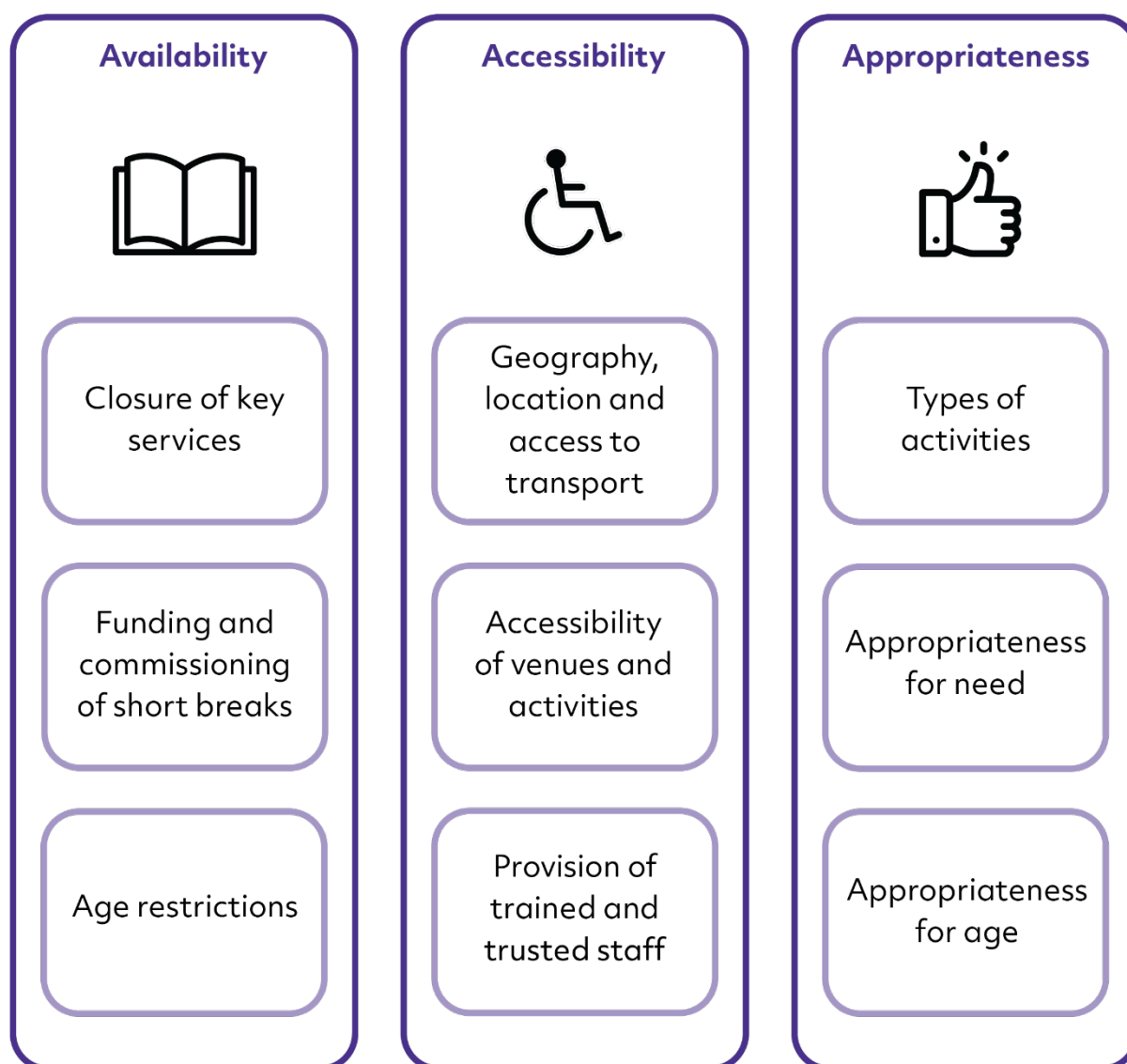
“I have no idea! Nobody’s ever asked me that. I don’t know what to say. I’ve never been asked that – what would I like to do?”

...I’m so used to being at home. I almost sometimes feel scared to go out, I haven’t had many social opportunities in my life really.”

- Disabled young person (school leaver).

Availability and suitability

The availability, accessibility and appropriateness of the short breaks offer for disabled children, young people and adults was a key theme amongst all three participating groups.



Across all three participating groups, it was possible to identify a range of factors that were said to contribute to the challenges identified in the availability, accessibility and appropriateness of the short breaks offer in Gloucestershire:

- All groups spoke about a **shortage of services** available for the level of demand in the county. **75%** of surveyed providers said they had sometimes, often or always been unable to provide short breaks support to families due to high demand and the same proportion wanted to be able to provide more of the services they currently provide.
- Parent-carers noted how an already challenging situation has been exacerbated by the **Covid-19 pandemic** and the enduring impacts of the restrictions that were imposed.
- Several factors or features were identified as being essential to the **accessibility** of short breaks and respite care activities. These were said to include: the proximity of activities to where people lived, access to transport, how easy it was for those attending the activities to take part, and the availability of trained and suitably qualified staff.

- There was a view amongst some parent-carers, children and young people that there was little provision in the county that they considered appropriate for their children. **29%** of parent-carers said that the **ability of providers to meet their needs** was a barrier whilst several spoke about a lack of provision for profoundly disabled children and young people.

We don't benefit [from] any respite of that [activity]. We take turns, you know, taking him to special yoga, you know, we can't engage in a lot of the after-school stuff that [provider] organise because it's after school and by the time we get there it's going to be too late, or [my son] is a bit tired by the end of the school day...the boxing [club] was a Friday night after school so we just about managed to get to Gloucester for that one. So that was travelling to Gloucester on a Friday, you can imagine that journey...took about an hour and fifteen minutes to get there for a 45-minute boxing session."

Parent-carers told us that rarely did overcoming one barrier grant the family access to the short breaks and respite care provision they sought. Instead, as shown in a series of graphics that follow, overcoming one barrier was often said to lead to another. Those who could access short breaks often went back to the start of the process when their child reached traditional milestones.

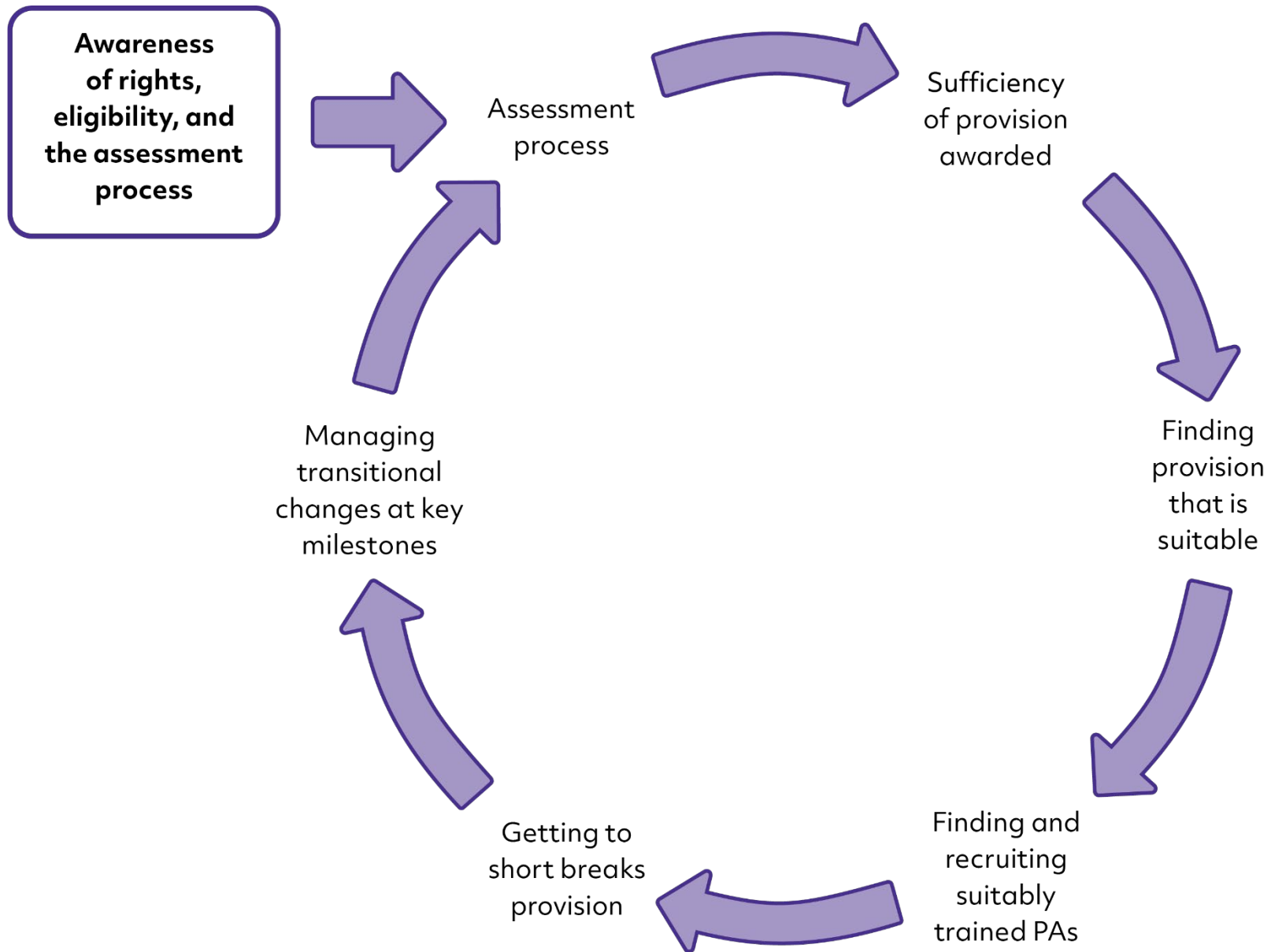
Scenario A | Assessed needs

For a child's needs to be assessed first requires parent-carers to have enough information and awareness to access the assessment process. As highlighted above, many families were unaware that they may be entitled to these opportunities.

Those who do enter the assessment process then go through a series of stages. This begins with the assessment itself (a process many parent-carers highlighted as difficult, worrying and stressful).

Parent-carers then told us about challenges if the level of provision awarded was too little, of there being limited suitable provision to choose from, and, often, having to find a PA that is suitably qualified to support their child.

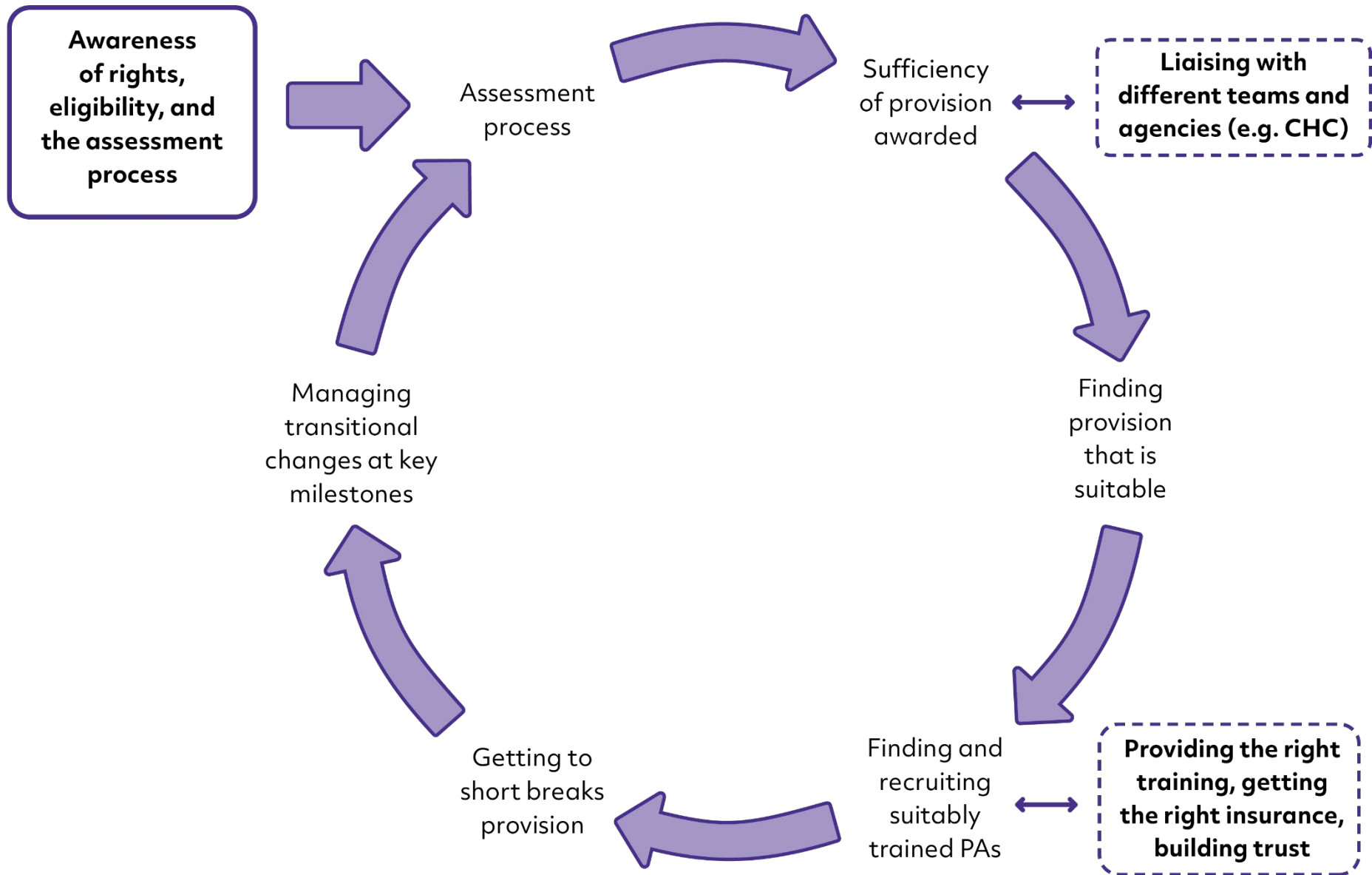
With this in place, parent-carers told us that there were often challenges getting to the provision they had found; either because it is too far away, at difficult times of the day or because of their own lack of transport.



Scenario B | Complex needs

Where children have complex needs, the barriers were said to become more complex to overcome. For example:

- Negotiations around what level of provision should be awarded may involve more agencies and teams such as Continuing Health Care (CHC).
Consequently, parent-carers described the need to “fight” on multiple fronts.
- The complexities of recruiting a PA (as above) are exacerbated further. As is the need to ensure the staff at activities have the necessary training to fully support these children’s needs. For example: knowing how to support someone who uses oxygen or follow epilepsy protocols. Even if somewhere has the right training, the parent needs to feel confident the organisation or PA is sufficiently insured and can be trusted.



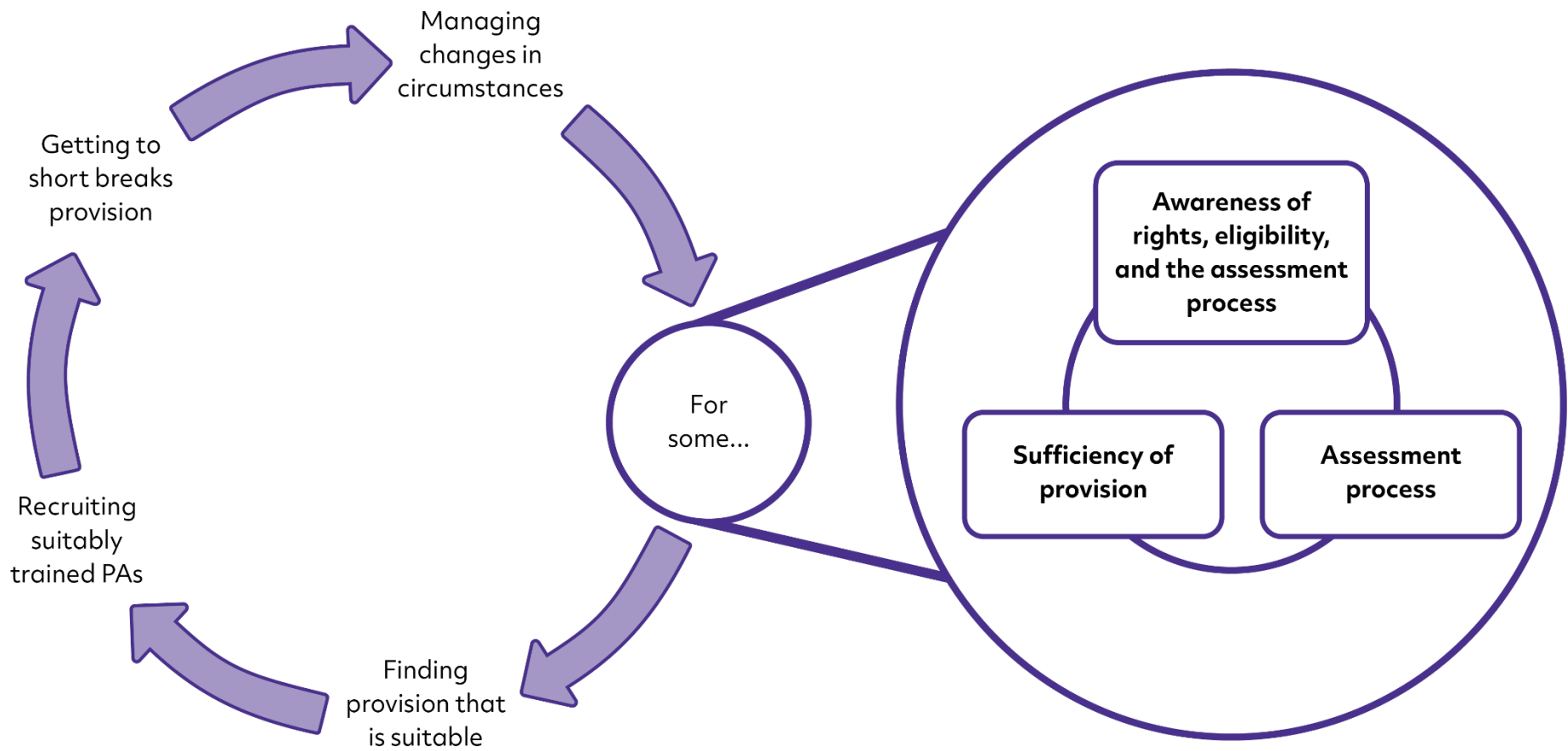
Scenario C | No assessment needs

In addition, there are many children with Special Educational Needs and Disabilities (SEND) who do not meet the threshold for assessed needs. Equally, there are many parent-carers who would not choose to seek commissioned services – either because they are happy with the activities they are accessing privately, or because they do not trust, or wish to go through an assessment that may not provide the outcomes they want.

Nevertheless, these families may too experience barriers to accessing short breaks and respite care. Unlike above, where the first challenges are at the assessment stage, for these families the cycle begins with the search for suitable provision.

These children still have additional needs that require support and so these families may still need to find a PA with the right understanding of their child's needs, or need to trust a setting is able to look after their child in the way they need. Likewise, they still need to be able to have the means to access the provision (such as access to a vehicle or public transport).

These families too may reach a time where their child's needs change or their child is at an age where they can no longer access the same opportunities they once were. In these cases, some parents will return to search for alternative provision, but others may find that they need an assessment to access more specialist services.



How do we build a service that works for all?

Everyone who participated in the research was asked about what their ideal provision might look like. The responses to this question highlighted that, whilst there was a great deal of shared experience in the barriers to accessing short breaks and respite care, what individuals told us they wanted points to the importance of individualised solutions.

To this end, the following graphic summarises seven principles for quality short breaks and respite care provision that have emerged through participants' responses. These **seven principles**, if adopted as the underpinning priorities for short breaks and respite care, have the potential to build a service that works better for everyone: the local authority, the providers, parent-carers, and disabled children and young people.



What is Barnwood doing?

The findings of this research are being used in two ways:

- **Funding** | The original aim of this research was to inform a round of themed funding with a brief to be co-designed with parent-carers and disabled young people. This brief was completed in early-2023 and the call for applications launched in April 2023. Providers were encouraged to apply for up to £60,000 to participate in a year-long test and learn project in which innovative solutions to some of the challenges highlighted in the research could be piloted. The findings of these pilot projects will be evaluated and all learning shared with relevant stakeholders.

More information about Barnwood's themed funding can be found on the Trust's website:

www.barnwoodtrust.org/funding

- **Convening and engagement** | Recognising that many of the challenges highlighted in this research cannot be solved with funding alone, the Trust is also committed to engaging with stakeholders, including the local authority, to seek solutions to the significant challenges identified, including around assessment and access to information.

In October 2022, an engagement event was held with parent-carers, young people, providers, commissioners and the, now former-, Director of Children's Services. In May 2023, the conversation continued with the new Director of Children's Services and other colleagues within the local authority to talk about the research findings. Further conversations and collaboration are planned.

If you would like to get in touch about the 'Barriers to short breaks' research contact Dan Jacques (Lead Researcher) on **01242 539935** or at

dan.jacques@barnwoodtrust.org

Acknowledgements

Barnwood Trust would like to thank all of the parent-carers, young people, partners and stakeholders who took the time to share their expertise for this research and for their continued support as the work enters its next phase.

For more information about the 'Barriers to short breaks' research, including copies in alternative formats please contact Dan Jacques on **01242 539935** or dan.jacques@barnwoodtrust.org

Accessibility

This report contains a summary of the findings from the research. A full report and accessible versions of this research are all available through Barnwood Trust's website: <https://bit.ly/3KSQbkX>

Or scan the QR code to go straight to the accessible versions of the report



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