

Full
Report

BARRIERS TO SHORT BREAKS

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

August 2023



Acknowledgements

Barnwood Trust would like to thank all the parent-carers, and children and 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

Accessibility

This report contains the full findings from the research. An executive summary 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 reports



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Background

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 project follows the findings of **Our Changing World (2020)**¹ in which access to short breaks and respite care was highlighted as one of eight areas in which disabled people and people with mental health conditions were disproportionately impacted during the Covid-19 pandemic.

This earlier report found that restrictions introduced to protect people forced many providers of short breaks and respite care services to close (indefinitely in some cases) and parent-carers to manage increasing care responsibilities without support from professionals or family members. Ultimately, we heard how the pandemic had caused carers and disabled people to experience unique challenges that impacted their mental health. In general, the pandemic highlighted the significance of these services to the emotional and physical wellbeing and resilience of parent-carers and their children.

The findings of this current research are being used in several 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 are 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 can be piloted.

The learning from these pilot projects will be shared with relevant stakeholders. More information about the themed funding can be found on the Trust's website: <https://bit.ly/3OKpmkW>

- **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 more significant challenges, including around assessment and access to information. In October 2022, an engagement event was held with parent-carers, young people, providers, commissioners and the then Director of Children's Services to share the research findings. Further conversations and collaboration are planned.

Definitions used within this report

Within this report, the following terms are used frequently:

- Parent-carers
- Children in Need
- Short breaks and respite care

Here, they are defined in the following ways:

Parent-carers refers to the parent of anyone with a disability: whether that person is a child (under 18 years old), or an adult.

Children in Need is a label utilised by social services to identify children who may be in need of additional care and support. Within their review of Children in Need on 2019, the Department for Education² defined these children as follows:

Children in Need are a group supported by children's social care, who have safeguarding and welfare needs, including:

- Children on Children in Need plans
- Children on child protection plans
- Looked after children
- Disabled children

All of these children have needs identified through a children's social care assessment or because of their disability, meaning they are expected to require services and support in order to have the same health and development opportunities as other children.

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.

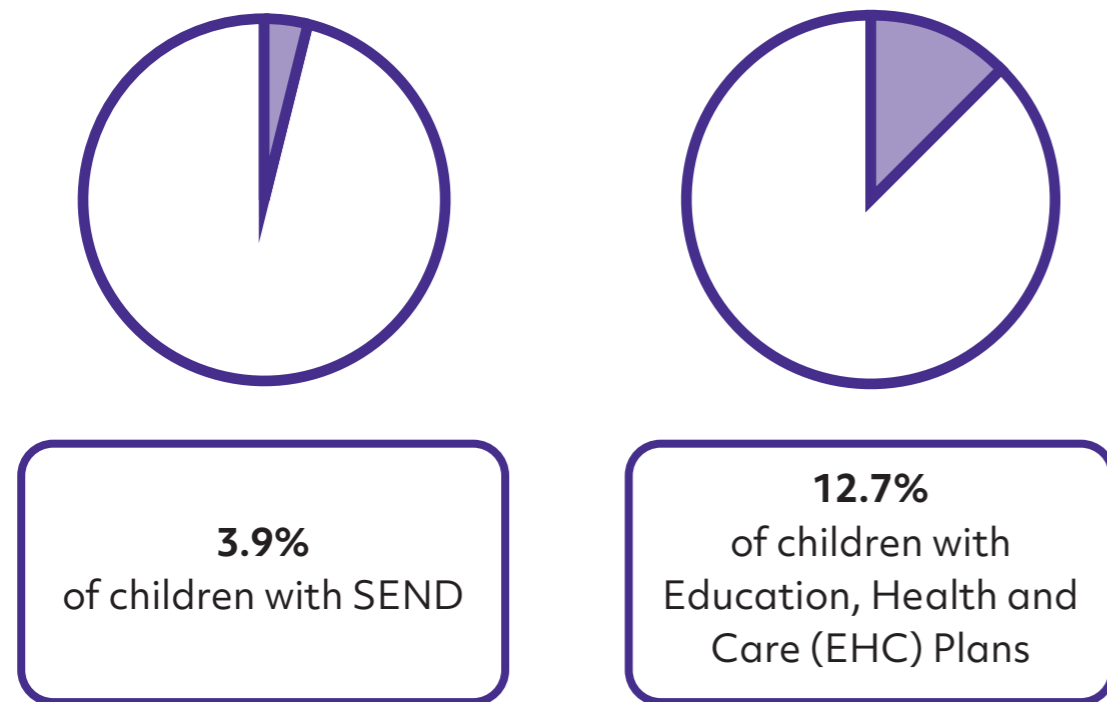
This means that many parent-carers of disabled children require specialist provision to get the breaks other parents might have.

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.

In context | Short breaks in Gloucestershire

During an interview with a, now former, commissioner from Gloucestershire County Council (October 2022), we were told there were approximately 618 children in the county who had been assessed to have social care needs (i.e. that they were eligible for short breaks and respite care).

Comparing this data with publicly available data about Special Educational Needs and Disability (SEND) in Gloucestershire³, shows this to be equivalent to:



Local government data shows that in the year ending 31st March 2022, Gloucestershire had the highest number of referrals to children's social care of its neighbouring areas (9,394) and the ninth highest of all English single tier and county councils⁴. The county also has the tenth highest number (nationally) of re-referrals to children's social care within 12 months (2,304)⁵.

The data also raises questions about assessment and resourcing within the county. Between 2014/15 and 2021/22 there has been a 133% increase in the number of Section 47 (child protection) enquiries within the county⁶. In 2021/22 alone, nearly 2% of all Gloucestershire children were under a Section 47 enquiry.

There has also been a large increase in the number of Initial Stage Child Protection Conferences (ICPC) held and Child Protection Plans issued – but not at the same rate. As such in this time period, the proportion of Section 47 enquiries leading to an ICPC has fallen from three-quarters (75.1%) to less than half (46.4%)⁷. Furthermore, those leading to Child Protection Plans has fallen from around half (53.2%) to fewer than 2 in 5 (39.7%)⁸.

Professor Luke Clements, Cerebra Professor of Law and Social Justice at the School of Law, Leeds University, has researched extensively on how local authorities across England assess the needs of disabled children, finding many investigate families through a safeguarding lens⁹ and few social workers to have specialist knowledge of disability¹⁰.

Local government data also provides figures around staffing and shows Gloucestershire to have had an above average turnover of children and families social workers in the year ending 30th September 2022 at 21.6%¹¹.

This is the equivalent to 1 in 5 social workers having left the team in the year. In the same period, there were 91 vacancies (full-time equivalent)¹² for children and family social workers, all of which were being filled by agency staff¹³.

What do we know about the impact of not receiving short breaks?

Several studies from the Covid-19 pandemic highlighted significant challenges being experienced by disabled children and their families when they could not access short breaks and respite care support:

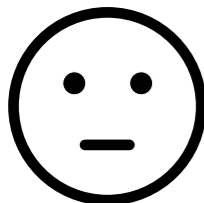


Providing additional care

According to Carers UK¹⁴, **38%** of families were providing more care because of local services reducing or closing during the first national lockdown in 2020.

Emotional impact

The Disabled Children's Partnership¹⁵ surveyed parent-carers about the mental health and wellbeing impacts of not being able to access short breaks and respite care services



- **32%** said their own mental health was a lot worse
- **30%** said their disabled child's mental health was a lot worse
- **19%** said the mental health of their disabled child's siblings was a lot worse

Physical impact

The same study also asked parent-carers about changes to individuals' general health:



- **18%** said their own general health has got a lot worse
- **11%** said their disabled child's general health has got a lot worse

Financial impact

Contact's 2021 Counting the Costs report¹⁶ highlighted how:



- **33%** of parent-carers had to quit a job due to a lack of childcare or respite care for their disabled child
- **27%** work fewer hours due to their childcare and respite problems.

Although these studies were completed at a time of a global pandemic, the impact of an absence of services was not unique to this time. Twenty years ago, in 2003, Mencap published their first Breaking Point report¹⁷ which highlighted challenges for families in accessing short breaks.

Ten years later, Mencap repeated the study and found that¹⁸:

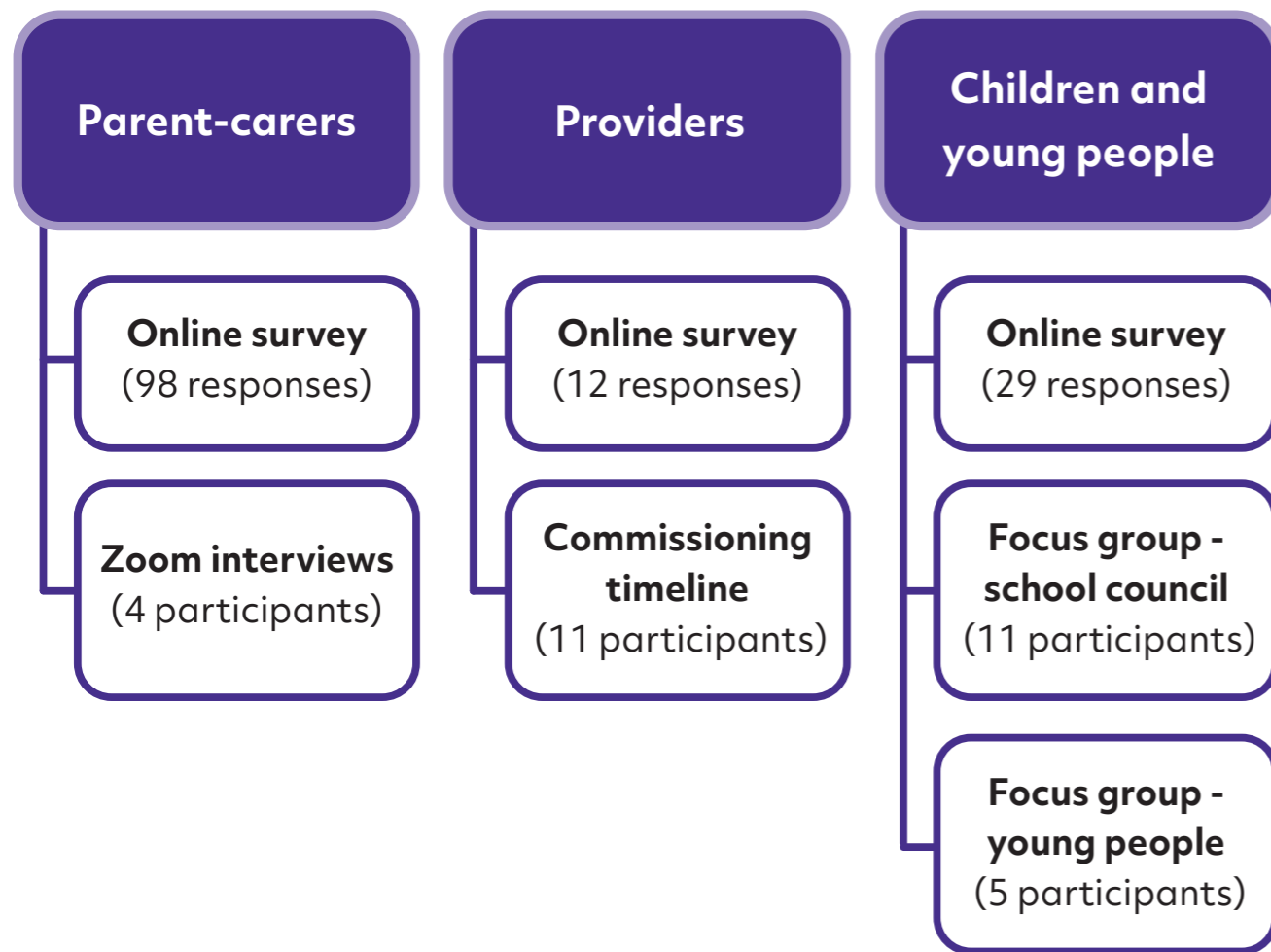
- **8 out of 10 family** carers have reached, or are close to reaching, breaking point due to a lack of short breaks
- **9 out of 10 family** carers report high levels of stress
- **8 out of 10 family** carers claim that a lack of short breaks has had a negative impact on their family life
- **Half** of carers say that their caring situation has led to them giving up work altogether or seriously considering doing so

Methods

As far as possible, the focus of 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.

An exploratory phase helped to identify key areas to find out more about, who to speak to and how we should ask our questions.

The graphic below outlines the research methods used with each participating group:



In total, 103 parent-carers*, 29 disabled children and young people and 12 participants from local short breaks and respite care providers responded to their respective 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 much of the focus group with young school leavers.

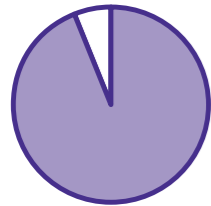
The topics covered varied slightly between groups based on the feedback gathered through the exploratory phases of the research design. Parent-carers were asked about their experiences of the process of being assessed for short breaks and respite care eligibility and the availability of provision. Providers, on the other hand, were asked about their capacity, demands on their services and about the way services are commissioned. Young people were asked about what they do in their free time, what they would like to do more of and what say they have in the opportunities they can access. All three groups were asked about the challenges they experienced and of their ideal provision.

All the data was gathered in line with Barnwood Trust's Research Code of Practice¹⁹.

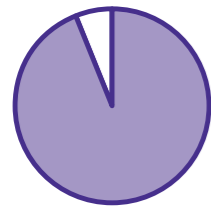
*Five responses were not included in the analysis because the responses indicated the participant not to be a parent-carer. Their answers indicated they were carers for spouses, parents or other family members which was outside of the scope of this research.

Findings

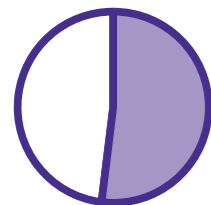
The research findings indicated that parent-carers, providers, and disabled children and young people in Gloucestershire were experiencing a range of barriers and challenges to accessing short breaks and respite care:



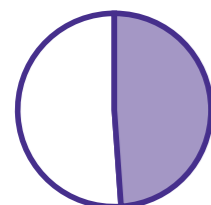
94% of parent-carers told us through the survey that they were not currently accessing all the short breaks they felt they needed.



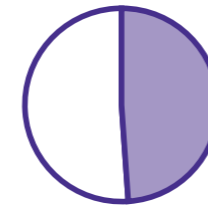
93% of parent-carers told us through the survey that they had experienced at least one barrier to accessing short breaks provision.



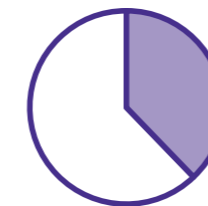
52% of disabled children and young people told us through the survey that they were not attending groups or activities after school or at the weekend.



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



49% of parent-carers told us through the survey 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:

- challenges to do with **assessments** for eligibility of short breaks and respite care support.
- difficulties accessing **information** about short breaks and respite care, and a lack of clarity and consistency in the **information** that is available.
- a range of factors impacting the **availability** and **suitability** of short breaks and respite care provision in Gloucestershire.

These three themes are explored in more detail below.

Barriers to accessing short breaks | assessment

In the survey, **43%** of parent-carers said they had experienced assessments for eligibility for short breaks and respite care to be a barrier to accessing these services.

The process of being assessed for eligibility to access commissioned short breaks and respite care services was predominantly mentioned as a barrier for parent-carers. Their responses included accounts of:

- how the process was “confusing” and lacked explanation
- the need to navigate between several departments within social care and, at times, health – all of whom were said to disagree with who should be responsible for the assessment and provision
- how the process involves providing “masses of personal information”
- how assessments were perceived to be predominantly about safeguarding – rather than the family’s wider needs. Parents told us they were fearful of asking for help in case their child was taken away from them
- how the process was felt not to take account of the wider context in which families were living:

“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

Several parent-carers also reflected their concerns about how assessments were conducted, including:

- concerns about inconsistencies in the way assessments were undertaken and in the information they received about their eligibility for short breaks and respite care
- concerns that the bigger picture was not being taken into account and the effect of this on their assessment outcomes
- a fear that they, and their parenting abilities, would be judged for asking for help – this was connected to a perception that their parenting would be blamed, and by the use of social workers who specialised in safeguarding rather than in disability
- concerns about the outcomes of their assessment. Several people spoke about whether going through this process felt worthwhile

Furthermore, several parent-carers also spoke about their perceptions of the eligibility criteria for meeting the threshold for assessed needs entitle them to access short breaks and respite care support. As with their views on the process of assessing for eligibility, many parent-carers also perceived the criteria for eligibility to be applied inconsistently or in ways that were not fully transparent.

Comments about the eligibility criteria included:

- that their child was not deemed sufficiently disabled so as to require social care despite the parent-carers feeling they needed extra support. There were examples where eligibility was refused on the ground that a child was mobile or that a child’s neurodiversity was not considered sufficiently debilitating to need short breaks support

- the circumstances of the family being used as a justification for why their child was not considered to need short breaks or respite care support. Examples included because their child was attending a special school, because both parents were working (and thus, one could cease working to care for their child), and a belief that their child's needs were already met via other means
- the age of the child – particularly where children were younger than eight years old
- how their status as adoptive parents restricted their entitlement to other support
- A lack of transparency and a belief by one parent that decisions are made based on “any list of reasons they are using on a given day”

Only a lack of information (**49%**) received a higher response rate.

Barriers to accessing short breaks | information

All three participating groups commented on a lack of available information on short breaks, that the information which is available is often not of sufficient quality and of how such challenges are 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. Examples included:

- feeling they had to chase the local authority for answers or to be the one driving the conversations to make progress in their attempts to gain more information
- a view from some that the information they did receive was not of very good quality or that the information was given inconsistently – causing confusion
- how the lack of clear and consistent information caused some to feel unsure about what was available, about their rights and entitlements, and, in some cases, about exactly what short breaks were

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.

These views were similarly held amongst the providers we spoke to:

- breakdowns in communication between the local authority (LA) and local providers were said to have resulted in delays that almost put these organisations at risk
- there was said to be a reliance on other organisations to gather the information they needed to stay up-to-date with what was happening – especially around the recommissioning of short breaks
- Providers said they were often required to chase the local authority for responses
- There was a lack of clarity and a great deal of uncertainty about both the present situation and what the future might look like. Such uncertainty was said to prevent providers from being able to offer certainty and reassurance to their staff and the families they support

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.

“I was about to hit the two-month notice period where I didn’t know I had money to pay for them from the 1st April, and on the very last day when I had approached and phoned and chased, I got the email confirming it which meant I could send out.”

- Provider of short breaks and respite care for children and young people

“It’s difficult to get an assessment and information about respite breaks, short breaks, are not readily available. Carers don’t have the time and energy to research, hence missing out.”

- Parent-carer of a disabled young person

Many disabled young people also reported how they had been unable to communicate their needs or preferences – especially to professionals and providers – as they were rarely or never asked.

When asked about the information they had been given and their opportunities to communicate their needs or wants to providers or professionals:

- **38%** of young people said they had never been asked about any aspect of the support they were receiving
- most commonly, respondents said they had been asked about their support needs (**31%**), their care needs (**31%**), their communication needs (**24%**), and their preferred activities (**24%**)
- **no participants** said they had been informed about alternative groups, **7%** had been asked their preferences for group size, and **14%** said they had been asked about their sensory needs

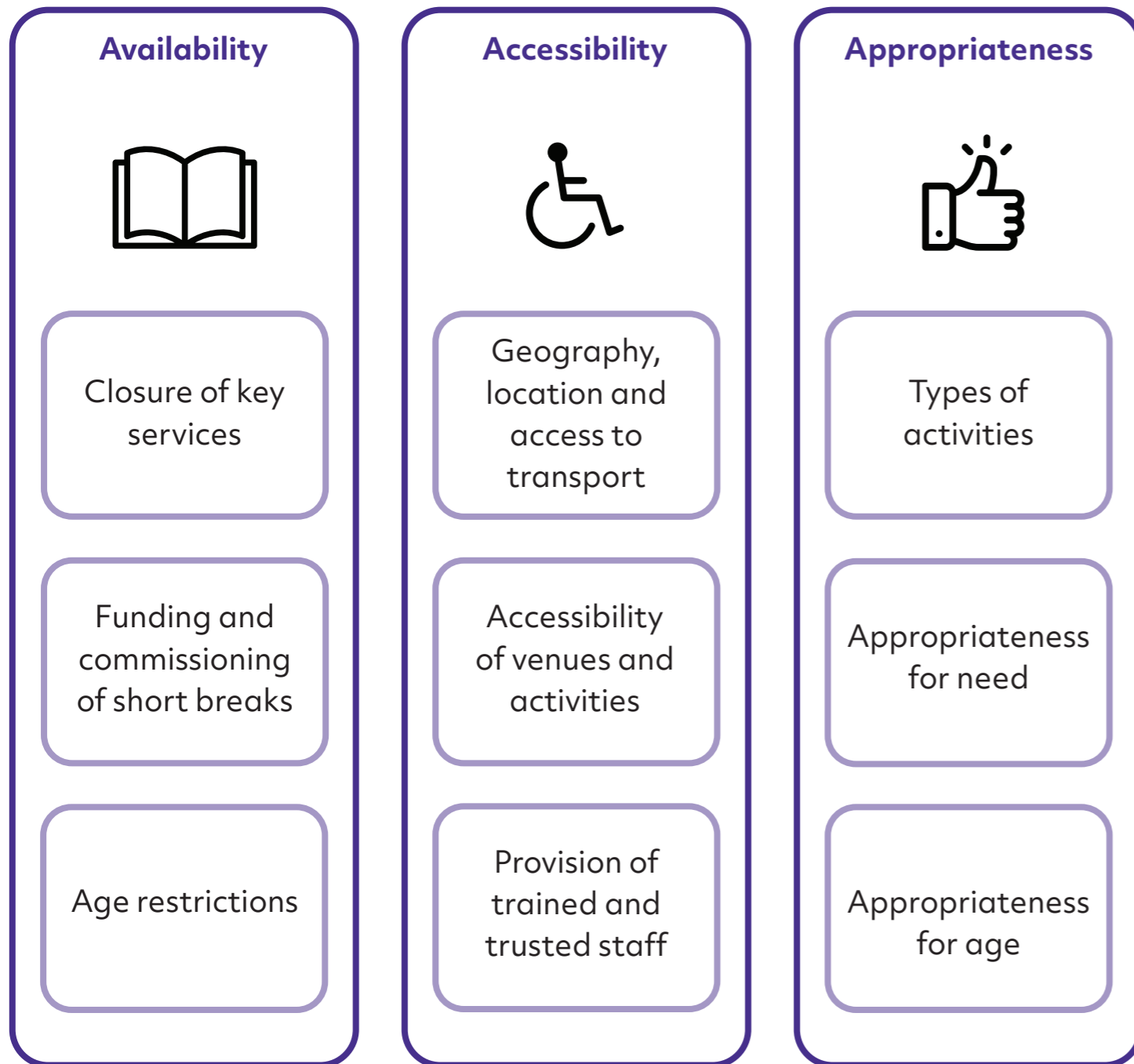
In a focus group with young school leavers (aged 20 to 25), three of the participants shared how they had never been asked about what they might want or need from short breaks. This was further emphasised at one stage of the discussion when all five participants felt unable to answer a question about their ideal provision. Further probing highlighted that they had never been asked before:

“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? That throws me...to be asked what you like to do today – I don’t know – 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).

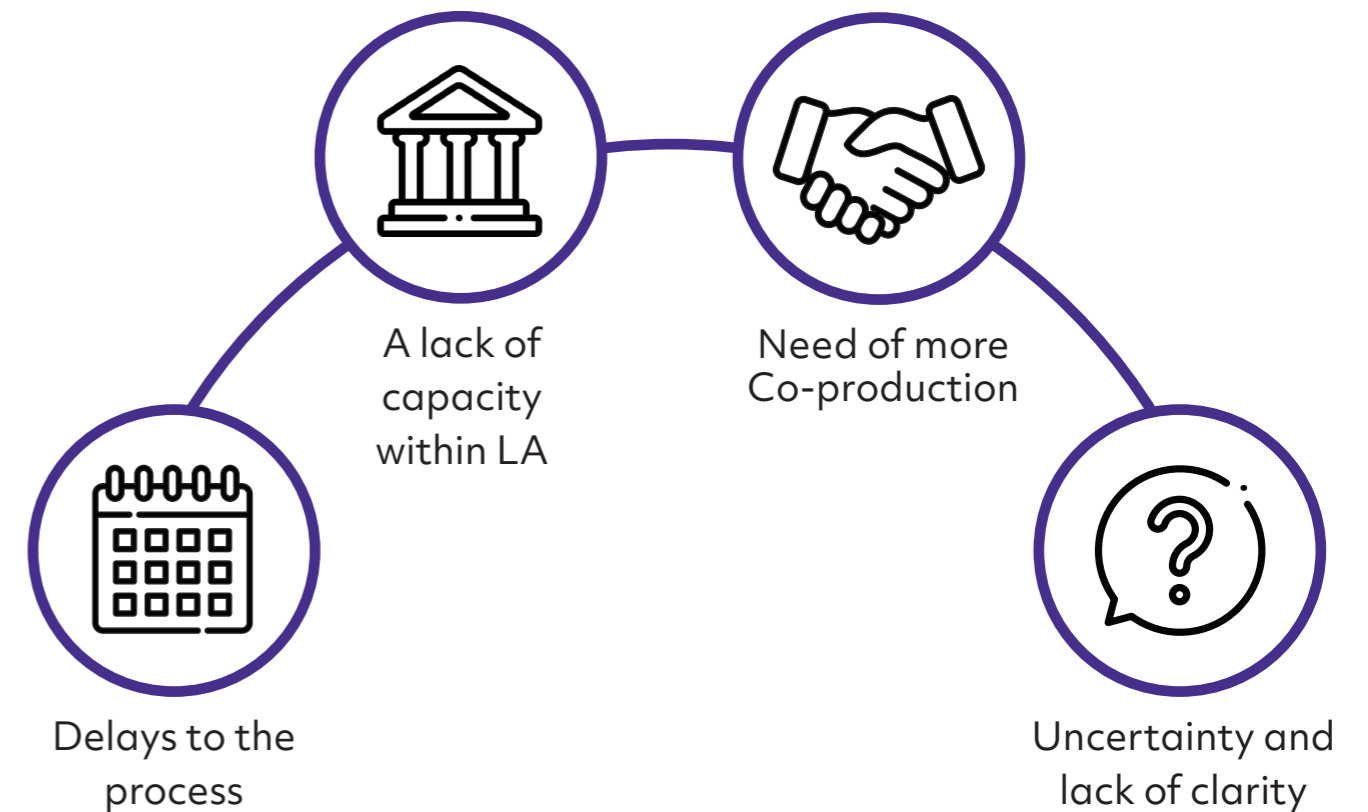
Barriers to accessing short breaks | availability and suitability

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



All three groups spoke about there being 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.

In addition, in a focus group with providers, we heard examples of how the challenges surrounding the recommissioning of short breaks and respite care in the county had negatively impacted the services they were able to deliver. Providers highlighted four key areas that needed attention before the next round of commissioning:



Parent-carers noted how an already challenging situation had been exacerbated by the Covid-19 pandemic and the enduring impacts of the restrictions that were imposed:

- some families had been unable to use their short breaks money and were not accessing any respite care during much of the pandemic
- some services which closed, as per national guidance, have been unable to reopen
- the closure of services during national lockdowns has meant that some providers are overwhelmed with demand and parent-carers have lost any flexibility to choose when they want to access particular services

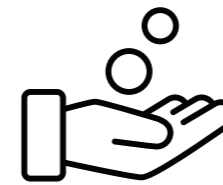
“Due to the severity of our son’s needs there are virtually no respite providers able to take him. The one we did use pre-Covid was not really convenient for us but we used it rather than not have any breaks. We have not had any respite since [March 2020] as due to Covid they closed the respite beds, then reduced it to only one when reopening. This meant we could not access the respite my son was allocated (reducing by more than half and also not able to offer school holiday/ weekend times) and times offered did not fit with our family.”

- Parent-carer of a disabled young person

Several factors or features were identified as being essential to the accessibility of short breaks and respite care activities. These were said to include:

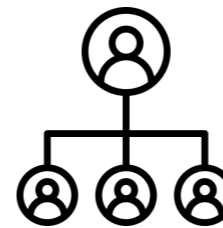
- the proximity of activities to where people lived
- access to transport
- how easy it was for those attending the activities to take part
- the availability of staff with suitable training

It was common to hear from parent-carers about the challenges they were having finding and recruiting personal assistants (PA) who could accompany their child to activities. Their perceptions of why this might be included:



Levels of pay

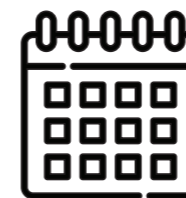
There was a feeling that the pay conditions of carers disincentivised individuals from working in the sector.



Levels of responsibility

The amount of responsibility required to support children and adults with complex needs. Again, the view was that other occupational sectors were more attractive.

Inappropriate work patterns



It was reflected that it was disproportionate to expect someone to potentially have to travel a long way, at their own expense, and only be asked to work for one hour. Such working terms and conditions were suggested as a reason why some families (especially those with lower entitlement to short breaks) were finding it so difficult to recruit PAs.

Family trust and acceptance



Beyond payment, there was also the challenge that whoever you recruit to care for your child needs to be accepted by the family. Parent-carers described a catch-22 between finding anyone who will be able to care for their child and finding someone who was trusted by the whole family - especially the child. Trying to do the latter could make it more difficult to access provision.

For those families who could find a PA or provision, several noted that the distance they needed to travel meant it was often not the sufficient break they wanted or needed, or that there were still barriers to transport which limited the opportunities they and their children could access:

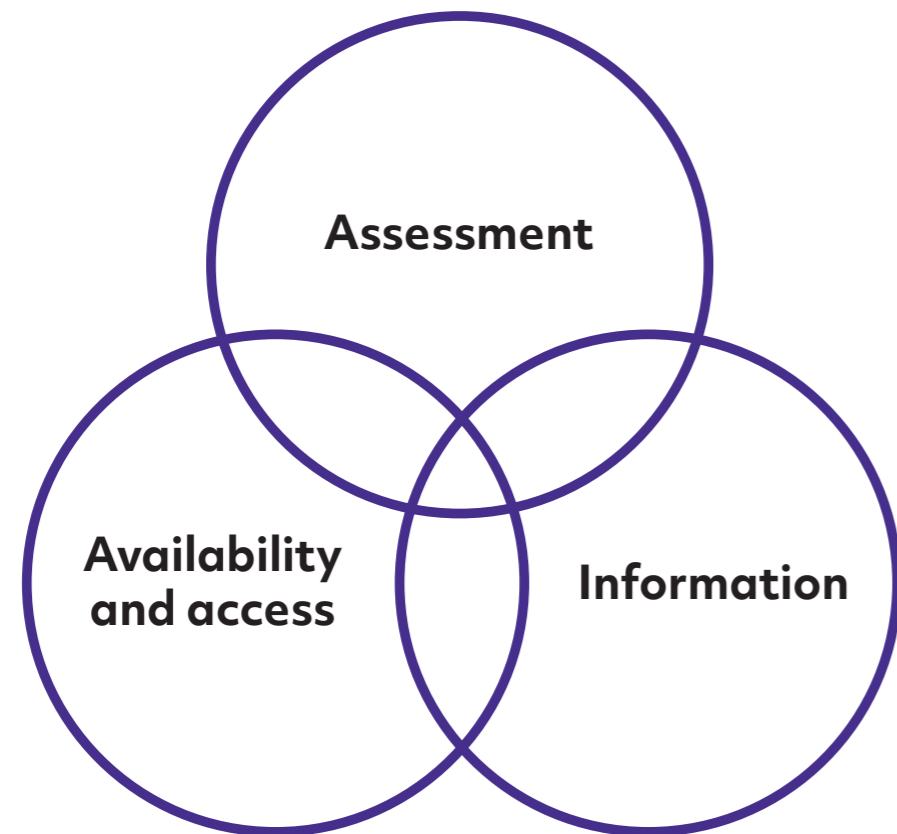
“We don’t benefit [from] any respite of that [activity]. We take turns, you know, taking him to special yoga, you know, we can’t engage in a lot of the after-school stuff that [provider] organise because it’s after school and by the time we get there it’s going to be too late, or [my son] is a bit tired 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-carer of a disabled young person

Finally, 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. Several parent-carers said the only short breaks and respite care provision they accessed was from a hospice care provider in another county. This service was said to be overstretched and availability was infrequent.

What happens when these barriers overlap?

As depicted in the diagram below, the barriers of assessment, information and availability are not mutually exclusive. They intersect and interact to create what parent-carers describe as an incredibly complex and, at times, impenetrable barrier:



Examples illustrating this interconnectedness include:

- the importance of having access to accurate and timely information about assessment eligibility, processes and rights to appeal
- how an assessment can often be a gateway to different or more specialist provision
- the need to be informed about what provision is available and to know more about the provision to be able to judge its suitability
- how accessing provision can itself be a source of information via keyworkers and other parents

Moreover, 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, overcoming one barrier was often said to lead to another.

Even where families overcome barriers and do gain access to short breaks and respite care provision, there comes a point where the child reaches an age milestone, their needs change or other factors trigger the whole cycle again.

The graphics that follow depict three common scenarios that appeared in the research:

- a) A child whose needs have been assessed as eligible for social care support.
- b) A child with complex needs who needs the most specialist provision.
- c) A child whose needs have not been assessed for social care support.

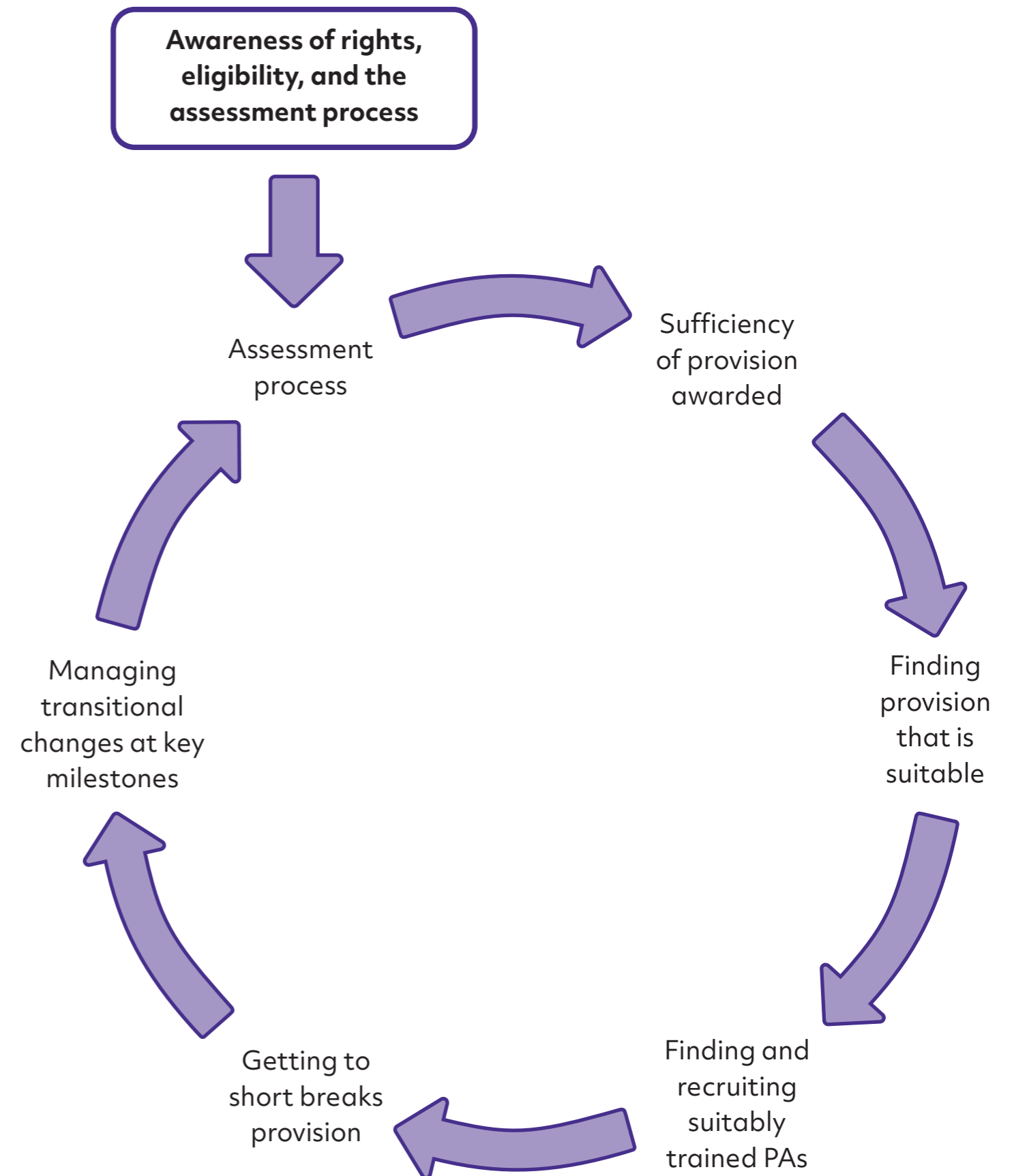
NB: These scenarios focus in particular on disabled children and young people as this is the group about whom the majority of data was collected.

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. Without this awareness, as highlighted above, many families were unaware of the potential for entitlement to these opportunities.

Those who do, enter the assessment process and a series of stages beginning 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.

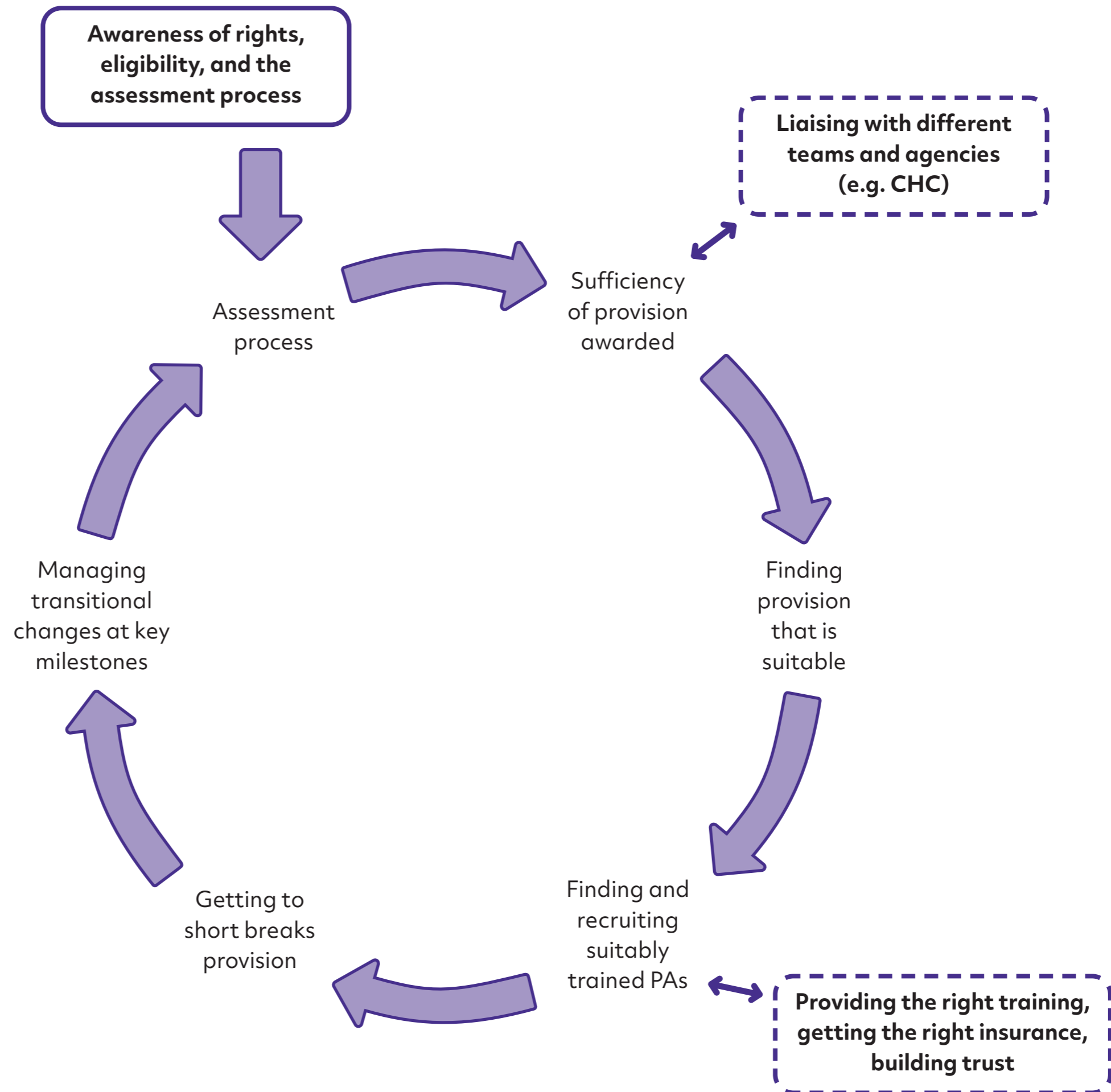
With this in place, parent-carers told us that there were often challenges getting to the provision they had found; either because it is too far away, at difficult times of the day or because of their own lack of transport.



Scenario B | complex needs

Where children have the most 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 evidenced 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 correct 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



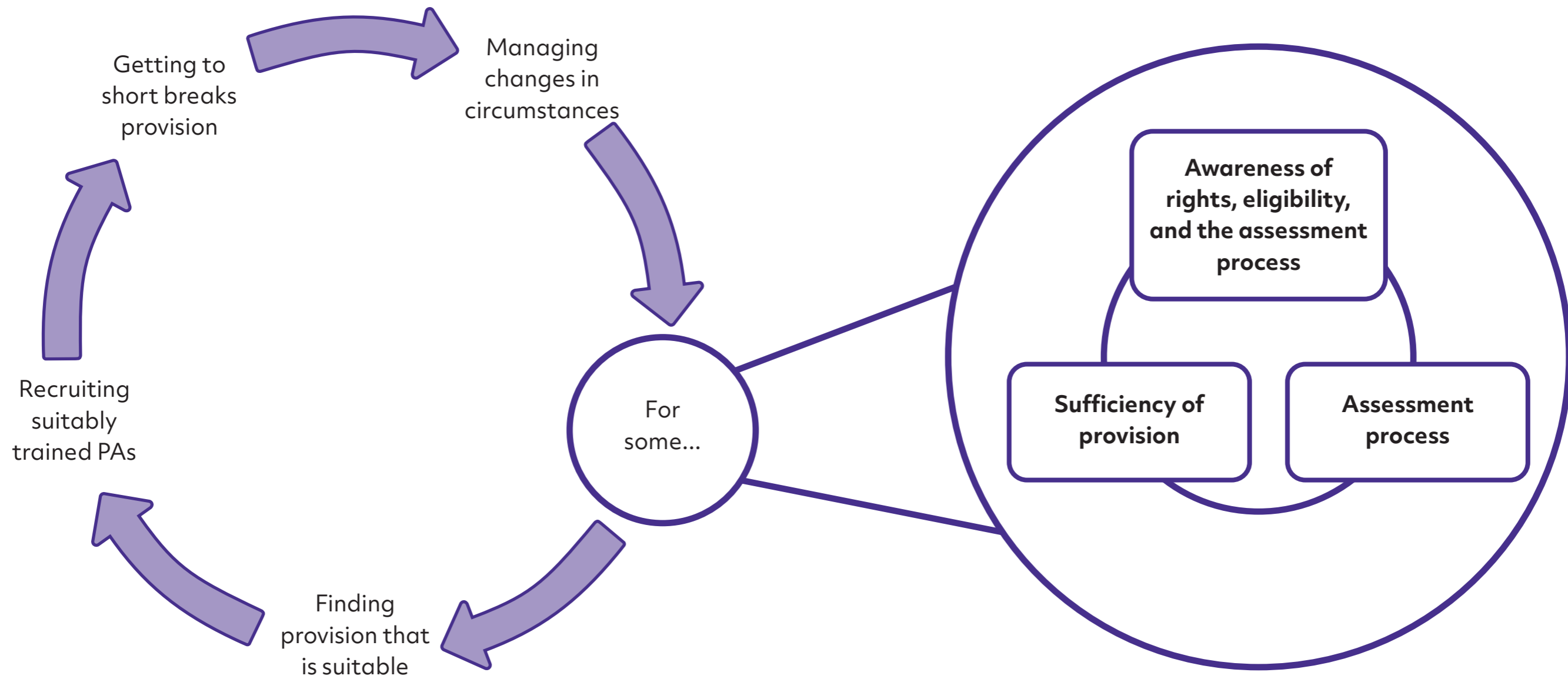
Scenario C | no assessed needs

In addition, there are many children whom will never meet the threshold for assessed needs, even if lowered. Likewise, 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 Scenarios A and B, 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 indeed find that they need an assessment to access more specialist services.



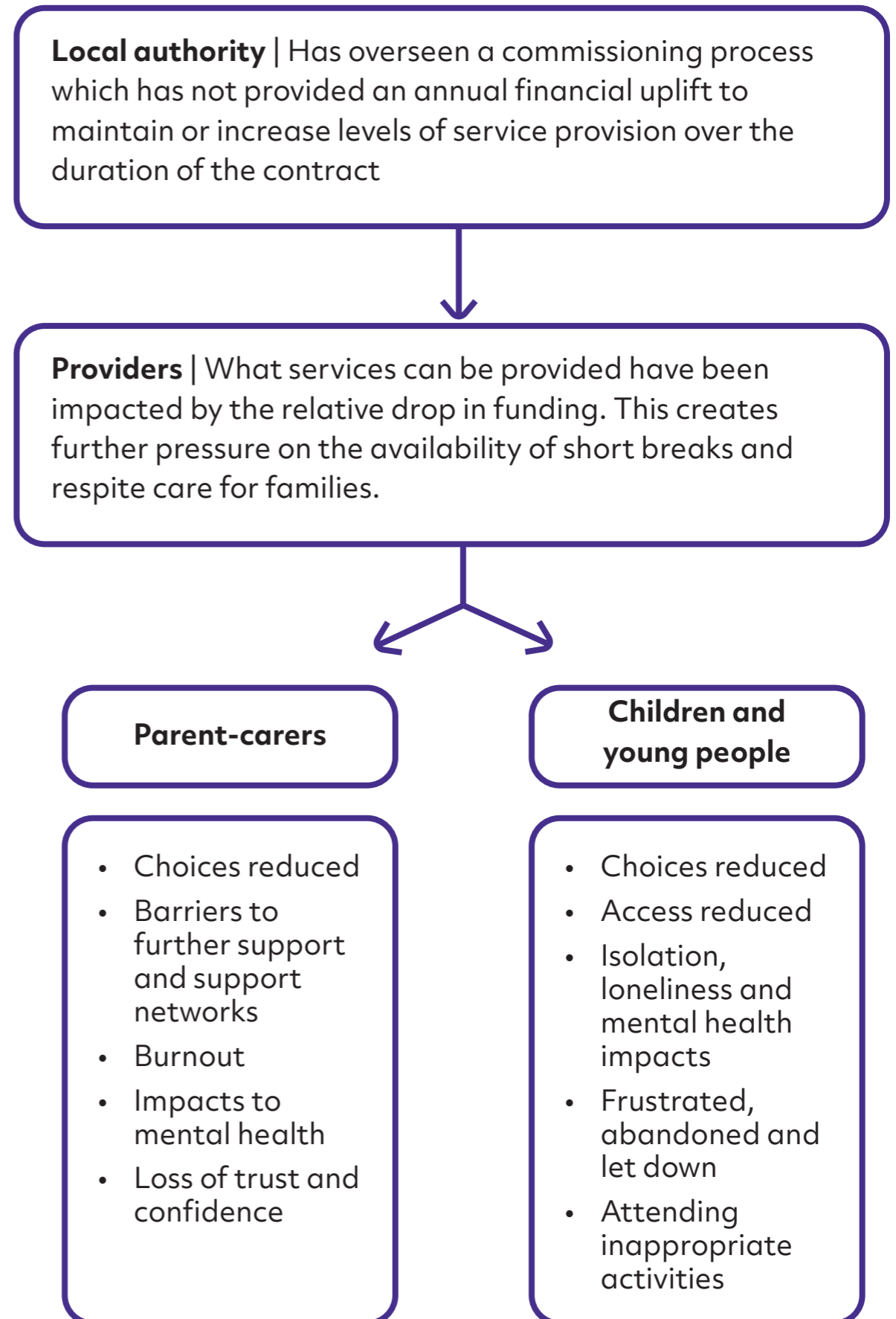
The impact of these barriers on parent-carers and disabled children and young people

Many impacts of the challenges they faced in accessing short breaks and respite care were shared by parent-carers, and disabled children and young people.

Often, decision-making, policies and/or procedures within the local authority were said to be a catalyst for difficulties that rippled through the experiences of providers, parent-carers, and disabled children and young people. The graphic opposite has been produced to illustrate just one example of where this is the case in relation to the availability and suitability of short breaks and respite care provision.

It highlights how one decision within the local authority – not to provide an annual financial uplift to the providers they commission – has impacted what the service providers are able to deliver, and how this contributes to the challenges around availability and suitability. These challenges, in turn, impact upon parent-carers and their children.

Moreover, the impacts experienced can compound one another. A parent-carer whose choice of activities is reduced by availability can mean a child attending inappropriate activities because they are all that is available. Likewise, the reduced access to short breaks for a disabled child can mean fewer breaks for parent-carers and cause them to burn out.

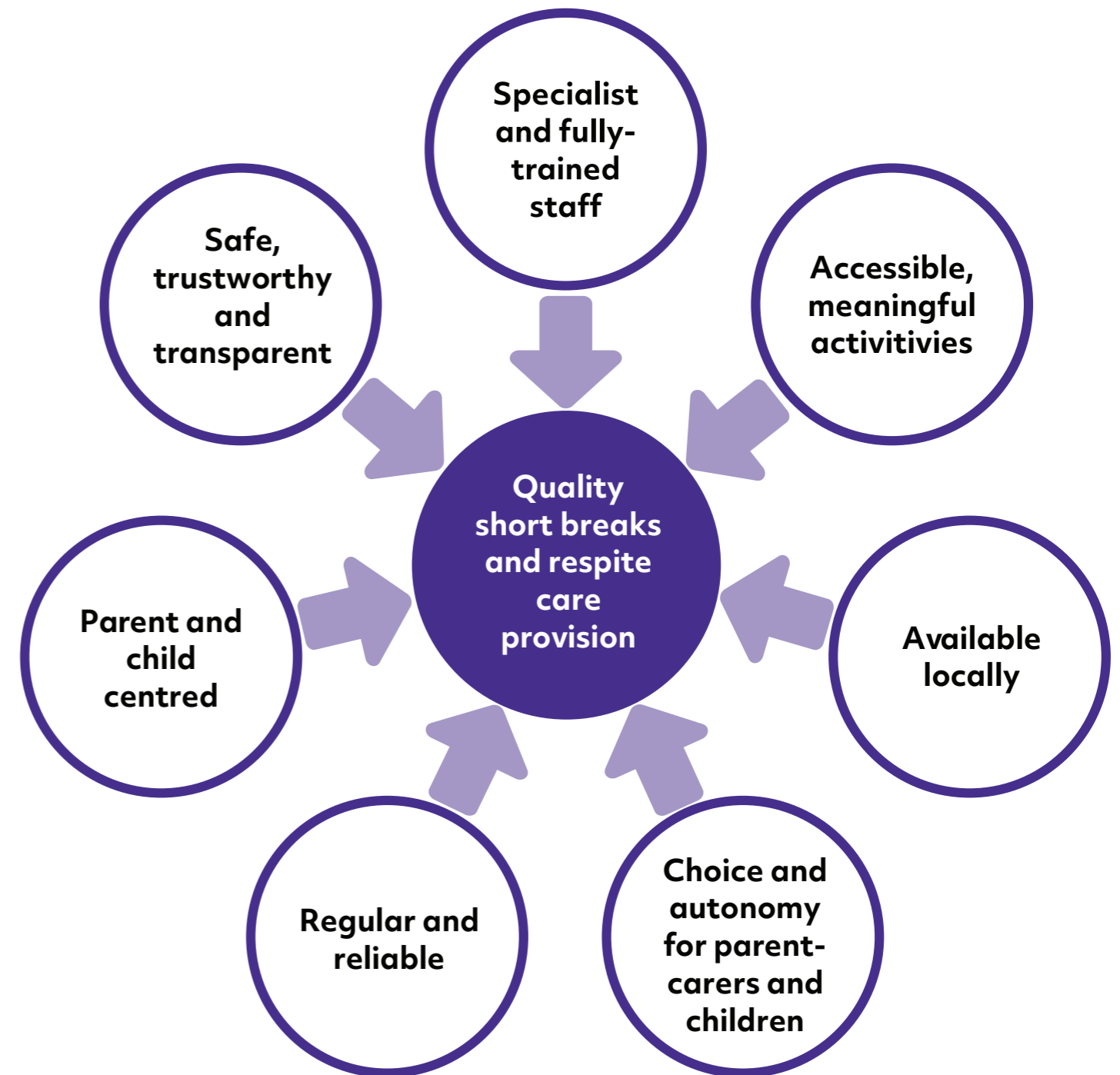


Building a service that works for all

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.



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We would like to say a huge thank you to everyone who took part in the research, we really appreciate it.

If you would like to find out more about the research, or request it in another format please contact:

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