Record Breakers

Local Authority Short Breaks Data on Disabled Children and Young People

Research by the Learning Hub at the Disabled Children's Partnership.

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Executive Summary

In England, local authorities are responsible for providing short break services for disabled children as set out in the Children's Act 1989[1]. Short breaks are services that enable disabled children to take part in activities and have access to the same opportunities as their non-disabled peers or receive care. They also give their parents or carers time away from their caring roles to work, study, spend time with friends or relatives or enjoy hobbies.

Statutory regulations require that local authorities must provide, so far as is reasonably practicable, a range of services which is sufficient to assist carers to continue to provide care or do so more effectively. This range of services must include:

Day-time care in the homes of disabled children or elsewhere

Overnight care in homes of disabled children or elsewhere

Educational or leisure activities for disabled children outside their homes and

Services available to assist carers in the evenings, at weekends and during the school holidays

Provision should also be flexible, reliable, accessible and culturally appropriate. Whilst universal and childcare services may meet the needs of disabled children and criteria for short breaks, they should not be instead of short breaks.

The Disabled Children's Partnership is a coalition of over 120 organisations that campaign for improved support services for disabled children, young people and their families. Our research conducted during the pandemic reported on the impact of the lack of support on disabled children and their families. The research revealed that disabled children and their parents from black and Asian ethnic minority groups experienced higher levels of isolation, anxiety and poor mental health than their white peer groups. Good short breaks provision aims to reduce poor outcomes for disabled children and their families.

Families of disabled children rely on support from education, health and social care. The wider project, of which this project is a part, focused on the social care needs of disabled children and young people and their families from black, Asian and mixed ethnic backgrounds. It was co-designed from inception to proposal with parent carers from ethnic minority backgrounds. The delivery of the project co-produced with parent-carers working as parent-researchers throughout the project. It was organised into the three phases below. This report outlines findings from phase three of the project.

- Phase one – Literature Review
- Phase two – Interviews with Parent Carers of disabled children
- Phase three – Secondary data analysis: Short breaks

Earlier phases of the project revealed that despite disabled children being defined as children in need within the Children's Act 1989, they are denied social care assessments and consequently do not gain support vital in allowing them to the same life opportunities as their peer group. Families that do receive an assessment, report a complex process that leaves them without sufficient support, with the provision of social care failing to meet their child's or families' needs. The aim of this phase of the project was to explore data about disabled children and short break services; evaluate experiences reported by families in phase two of the project within the wider context of short breaks provision and investigate evidence of inequalities in provision or utilisation by ethnicity.

Methods

The project was co-produced with parents of carers of disabled children from black, Asian and mixed ethnic backgrounds working as parent-researchers on the project. The learning from the co-production process is reported separately. Short break provision across England was explored from both the commissioner and provider perspective. Freedom of information requests were sent to all local authorities in England and parent-researchers scoped and reviewed all local authority websites for short breaks information. The aim was to understand if a range of provision as outlined above was secured by local authorities for the disabled in their areas. 99 responses from 154 local authorities were collated and analysed by the project team, with key findings presented below.

Findings

Responses from local authorities to our freedom of information requests demonstrate that local authorities are unable to report accurately the numbers of disabled children in their area. In addition, data held by local authorities about short breaks provision in their area is incomplete and lacks the information necessary to monitor services, to ensure they are flexible, reliable, accessible and culturally appropriate to support disabled children and their families.

As data is not comprehensively collected at local authority level it is not possible to understand equity of provision, monitor utilisation of services or assess outcomes for families using short break services. There is a lack of understanding about disabled children and young people's needs, both in terms of their disability and their ethnicity. We were unable to find any areas that provided targeted short breaks for families from black, Asian and Mixed ethnic minority groups, something that parents told us they would welcome during the earlier interview phase of our project. Responses showed that cultural needs were one of the lowest types of needs to be accommodated by short breaks.

Sadly, a dominant theme in the responses from local authorities regarding the needs of disabled children accommodated by short breaks was that universal services could accommodate all needs. Therefore, local authorities are not providing short breaks in addition to universal services. It is not realistic to expect that universal services, even those designed to be inclusive, to accommodate the range of support or provide the one-to-one support that disabled children with complex needs need in order to participate.

The review of local authority websites revealed that the information about short breaks is not easily accessible. This is not just in terms of what provision is available but also how to access it, who provides it and how the services meet disabled children's needs by way of their disability or ethnicity. Good level of information in an accessible format is necessary so that parents feel confident to leave their children at short breaks services. Poor information leaves parents contacting or attending multiple services that may not accommodate their child's needs. This experience adds to families feeling further marginalised and risks serious isolation and poor life outcomes in the long term. This is even worse for families who do not have English as a first language. Only three in ten websites had an option to change the language or contained a flag or symbol to support parents with language needs.

Conclusion

Local authorities are failing in their duty under the Children's Act 1989, to commission or provide appropriate short break services for disabled children and their families. An inability to report comprehensively about disabled children and young people in their area, both in terms of numbers and types of needs means the baseline local authorities should have to monitor services effectiveness is absent. This means that short breaks are not commissioned in accordance with need either based on disability, age or ethnicity.

Local authorities will be unable to monitor utilisation of services by ethnicity effectively. In addition, there is a lack of targeted short breaks based on ethnicity or that can accommodate cultural needs of families and websites do not consider the language needs of people without English as a first language.

Universal services do not meet disabled children's needs and local authorities reporting this are failing to apply government advice about their duties for short breaks and understand the needs of disabled children with disabilities or complex needs. The lack of understanding of the needs of disabled children who require or use short breaks, present a serious problem when assessing outcomes services hope to achieve and families need.

The review of short break providers, via website information reinforced our findings from the freedom of information responses and information vacuum that parents taking part in our interviews described. Lack of information or generic information leads to parent carers attending provision that does not meet their disabled child's needs. Withdrawing from short breaks, often on multiple occasions reinforces the feelings of isolation from others, with a negative effect on the families overall wellbeing.

Improved data is needed so that families understand about the short breaks process, how support is provided, by what organisations and routes for redress should services fail to meet their disabled child's needs. Transparency and accountability are needed to ensure families can be confident in using short break services. Ensuring avenues are available for disabled children, young people and their parent’s to be heard, preventing families dropping out of the system, further marginalised and isolated from society.

Recommendations

The government should:

- Carry out an audit of local authority’s registers of disabled children, and take action against those local authorities who are failing to meet their legal duty under the Children Act 1989 to maintain one.
- Work with local government and the disabled children’s sector to address gaps in data on disabled children’s services.
- Remind local authorities of their short break duties and review and re-issue the short breaks guidance, including lessons learnt from the Short Breaks Innovation Fund
- In doing so, pay particular attention to provision in the early years
- Include in the guidance specific advice on the support under the Care Act 2014 in respect of young people age 18-25 (and their families)

Introduction

The project was co-produced with parents of carers of disabled children from black, Asian and mixed ethnic backgrounds working as parent-researchers. The learning from the co-production process is reported separately. Parent-researchers provided input throughout the whole research process: from the selection of research methods, design of research materials, drafting research questions, data collection and analysis and reviewing final reports and dissemination materials. Parent-researchers also undertook interviews with parent carers of disabled children.

Short breaks offer disabled children the opportunity to meet with their peer group and spend time taking part in activities, experiencing new hobbies, building confidence and life skills. For parents, short breaks offer time away from their caring role, either for respite or spending time with their other children, friends and relatives or taking part in activities.

Short breaks provision when successful in meeting needs appropriately, facilitate positive wellbeing of disabled children, young people and their families and reduce social isolation. Although the focus of this project is the social care needs of disabled children and their families from ethnic minority backgrounds, other intersectional factors were also considered as part of this work. For example, the disabled child’s age and any needs arising from their disability.

The inverse care law is a concept frequently referred to when considering health inequalities. It refers to the pattern of services being located in areas with less need, rather than higher need. It also refers to the inequity of health services available for example, with people in more affluent areas having access to longer consultation times or advanced trained workforce. Over time it has become clear that such patterns exist across a range of services. This concept was used as a basis of the approach for phase three of the project.

Aims and Objectives

The aim was to collate data about short breaks provision for disabled children and explore the data for any disparity in provision by ethnicity. Short breaks data is not available as a published dataset, with data sitting with local authorities across England.

Data about short breaks provision was collated in two parts. Firstly, from local authorities using freedom of information legislation. This enabled us to explore the provision of short breaks from the perspective of the local authorities acting as commissioners of services. To understand the services commissioned by local authorities to meet the needs of families with disabled children and explore any inequalities by ethnicity that may be present. Secondly, we explored short breaks from providers viewpoint, reviewing the provision available across England.

Therefore, findings will be presented in two parts: short breaks services from the commissioners’ perspective and then from the providers perspective.

Methods

Part 1 – Commissioning of Short breaks.

The research team designed freedom of information requests, that were sent to all local authorities in England in May 2024. Under the freedom of information legislation, public bodies have 20 working days to respond to such requests. The topics selected by parent-researchers included the following areas:

- Number of disabled children in the local authority area (total and by ethnicity)
- Numbers of disabled children accessing short breaks in a 12 month period
- Short breaks services and spaces available
- Age range of disabled children using short break services
- Ethnicity of disabled children using short break services
- Short break services targeted to families from ethnic minority groups
- Needs of disabled children accommodated by short break services
- Short break services out of area
- Day and times of short break services
- The role direct payments play in the provision of short breaks

Part 2 – Provision of Short Breaks

Initially the same approach using freedom of information requests was selected, with providers in two areas sent our list of questions. As the range of short break providers varies across England from one local authority to another, it was decided it would not be practical to canvas every local authority and manage responses within the time frame available within this project. Two areas were selected with a greater proportion of disabled children from black, Asian and mixed ethic minority groups. However, insufficient valid responses were received.

Therefore, with the time still available within the project timescale, the research team instead reviewed information about short breaks in each local authority area. Parent-researchers developed a list of criteria to review the information available on websites. A small number of websites were initially reviewed to test the criteria used and although strategies were included to aim for consistency across the group of parent-researchers, bias between parent-researcher could not be completely ruled out. Criteria used to assess short breaks provision included the following:

- Dedicated short breaks page on local authority website
- Explanation of short breaks
- Type of short breaks available
- Criteria for a family to qualify for a short break
- List and number of short break providers
- Short breaks providers by disability and age
- Accessibility of information: language and disability
- Local Authority officer responsible for short breaks
- Costs for short breaks and associated costs (eg transport)

- Explanation of how disabled children are supported and staff avilable to support

The research team reviewed collated responses (FOIs received from local authorities and data collected from short break websites), with those with lived experience providing into insight into the information which was used to develop key findings.

Findings

Commissioning of Short Breaks

Responses to our freedom of information requests were received from 99 of the 154 local authorities across England. However, 30 local authorities informed us that they were unable to provide the information we had requested. The key reasons given were predominantly due to how information about short breaks was recorded. Multiple systems meant that information was not available in a reportable format, recording information would mean reviewing records of individual families manually or the information we requested was with providers and not the local authority. It was also common for local authorities to state that short breaks were commissioned on an individualised basis and therefore needs were also at an individual level and therefore could not be reported, as a population group. We did contact local authorities who were unable to provide information, to ask if some of the information was available however this did not yield further data.

Before discussing the data that we did obtain from the Freedom of Information, it is important to highlight what the inability to respond demonstrates, in terms of a local authorities role as a commissioner. If information is not available about the number of disabled children how are services commissioned to meet needs or review outcomes.

Disabled Children’s Register

The Children’s Act 1989 places a duty on local authorities to open and maintain a register of disabled children. However, 33% of local authorities did not hold a register of disabled children. In addition, a proportion of local authorities highlighted that the number provided was based on a separate source, as opposed to a disabled children’s register.

For example, rather than a total number of disabled children, numbers were provided for children in the following categories:

- Disabled children known to social care
- Children in need figures (disabled children are just one sub-category)
- Children with social work involvement
- Early help provided by local authority
- Census
- EHCP or SEN data, therefore children with special educational needs

Therefore, it is not clear how local authorities can plan and commission services for disabled children, short breaks or wider services, when baseline numbers for the group are not known. Just under half of local authorities that did provide a figure for disabled children were also able to provide the ethnicity of disabled children. However, once the local authorities that provided a different figure were removed, just 23% of local authorities that provided data reported a comprehensive figure for disabled children in their area.

Short breaks utilisation

It was expected that local authorities would be able to provide the number of disabled children accessing short breaks in a twelve-month period. However, once again the responses illustrated the lack of focus local authorities have around short breaks for disabled children. One in five of all local authorities responding were unable to tell us how many disabled children used short breaks.

Again, as with the disability register, there were constraints with the numbers provided with one in seven local authorities highlighting that they were only able to provide numbers for one type of short break, for example an overnight service or accessible sports session, rather than a comprehensive number across all short breaks services. In addition, one in nine highlighted that they were unable to tell if numbers reported were duplicated across more than one service. So, although numbers were provided, local authorities did not know if they reflected the same disabled children using multiple provision.

Just eleven local authorities provide utilisation figures for short breaks that included the ethnicity of disabled children. It was hoped to compare local authorities with higher and lower proportion of minority ethnic groups, to explore if there were differences in the uptake of short breaks. However, as the numbers supplied were not consistent or a comprehensive figure of short break services, this was unfortunately not possible to complete.

Short breaks services accommodating the needs of disabled children

During phase two of the project, interview participants told us about difficulties findings short breaks provision that met their disabled children’s needs and many experienced attending short breaks designed with a one size fits all approach. This could be younger children expected to attend sessions with a much older age group or a service that was unable to meet the needs arising from the children’s disability.

Just half of the local authorities that responded to our freedom of information request were able to tell us the age group that short break services in their area could accommodate. There were clear gaps in provision in the local authorities that did provide this information, with a third of local authorities without provision for disabled children under five years and half without provision for disabled young people 19-25 years.

Local authorities were asked how many short breaks were available for disabled children with the following needs listed in Table 1 below. Just 2 in 5 local authorities were able to tell us how many short break services or spaces were available for disabled children with needs defined below. The results are presented in order of the needs most likely to be accommodated by short break services.

Table 1: Types of needs short break service can accommodate.

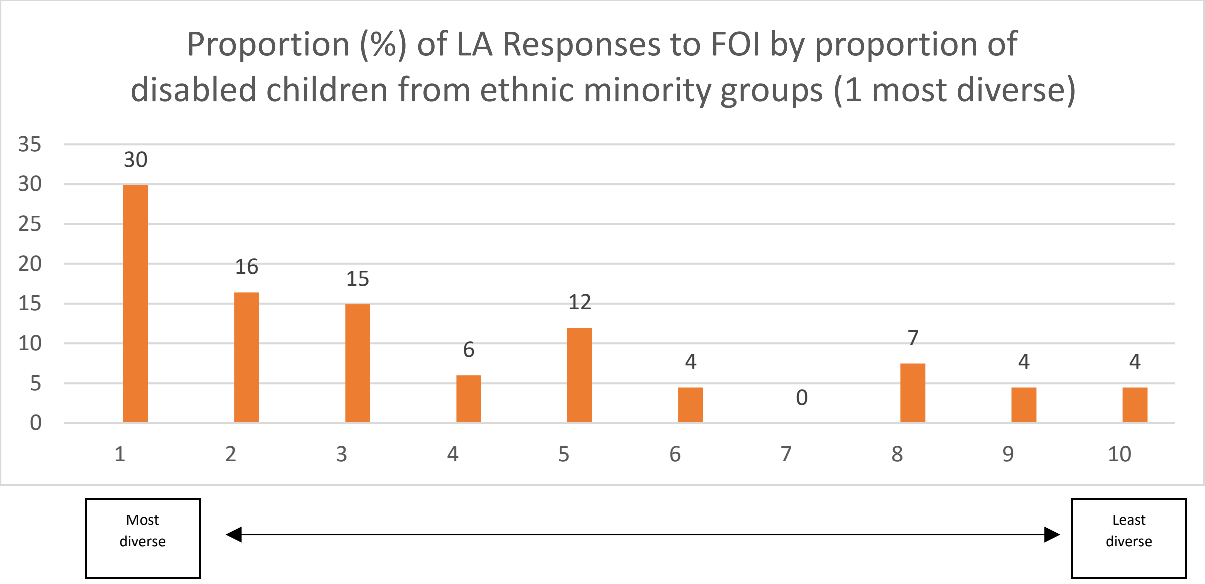
Needs	Proportion of short breaks can accommodate
Sensory	100%
Communication	99%
Personal Care	95%
Medication	93%
Dietary	93%
Wheelchair	67%
Hoist	53%
Gastro	50%
Cultural needs	29%
Oxygen	16%

It was clear from responses that despite the services designed for disabled children, they were not able to meet needs commonly expected from this group of children. The local authorities that were unable to provide specific figures related to the needs accommodated by short breaks commonly referred to the universality of services or reported that all services were accessible to all the needs in our list. However, they were unable to give us the number of disabled children in their area or using their service.

As demonstrated in Table 1, less than a third of short breaks accommodated the cultural needs of disabled children. Findings from parent carer interviews during phase two of the project revealed that families of disabled children from black, Asian and mixed ethnic minority backgrounds welcomed opportunities to meet other families from the same ethnic background who also had disabled children. However, none of the local authorities responding to our requests provided any targeted services for families with disabled children from the same ethnic group.

To investigate if this could be due to responding local authorities having less diverse population groups in their area, we reviewed responses by the proportion of disabled children from black, Asian or mixed ethnic groups. Local authorities were organised by deciles, with decile one group of local authorities with the highest proportion of disabled children from ethnic minority groups and decile ten being the least diverse. However, as illustrated in figure one, the majority of our responses were received from local authorities with the most diverse population groups. Two thirds of our responses were from local authorities on deciles one to four for diverse groups. Despite this there were no targeted short breaks provision commissioned and it was less likely that cultural needs of disabled children would be accommodated.

Figure one. Responses from Local Authorities by proportion of ethnically diverse population.



The lack of information provided about short breaks utilisation raises serious concerns about how provision is monitored by commissioners. How do short break services meet needs, if there is no information as to how many disabled children are using the services. It is also clear that disabled children not in the education age groups 5 – 18 years, are less likely to find provision locally and children who rely on wheelchairs or hoists or have gastro or oxygen needs are less likely to find short breaks that they can access. Therefore, although local authorities stated that short breaks are commissioned on an individualised basis, they were unable to tell us what needs services did meet and many services were unlikely to meet common needs that disabled children have by nature of their disability or cultural needs by way of their ethnicity.

Availability of short break services

Some parent carers taking part in interviews during phase two, talked about being able to access short breaks only when they had been assessed for direct payments, creating an additional barrier for access to activities. There were also instances were short breaks services expected them to stay with their child as the service could not accommodate their needs. Therefore, parents did not receive the respite that short break services were originally designed for. Parents also told us about travelling out of their local authority area as the provision closer to home was not available or there was a lack of provision at times the family needed, such as overnight or at weekends. We explored these issues when designing the questions included in the freedom of information requests.

None of the local authorities responding to our information requests reported that direct payments were a pre-requisite to using short break services. There was evidence that a small number of local authorities may require parents to stay at some short break services and reasons given were mixed in relation to this. For some it was related to a child’s needs, if the provider’s staff were not trained in a particular need or a child required 2-to-1 staff, then a parent may be required to stay. For other services it related to the type of activity, for example if it involved the disabled child getting ready for a sporting activity such as swimming then parents would be expected to stay to support their disabled child with their clothes.

A third of local authorities were unable to report if short break services were commissioned outside of the local area footprint. A third of local authorities responding to commissioner services out of the area, however such places were small in number. Less than half (45%) of local authorities were able to tell us the time or days that short breaks were available. It was most common for short breaks to be provided in the daytime, either weekdays, weekends or during school holidays. Less than half of the local authorities that provided the times of the short break provision, organised the provision during the evening or overnight.

To understand how local authorities monitored short break provision they commissioned we asked about the processes in place that enabled them to address any issues around low uptake of services. It was common for responses to discuss contract monitoring, usually on a quarterly basis, reviewing attendance figures at the provider however just one local authority referred to the involvement of parent carers in this process. The theme was more about increasing marketing of services to parents and social workers to highlight spaces available at short break providers rather than assessing if low uptake was about the quality of provision from parent carer or disabled child’s viewpoint.

Part 2: Providers of short breaks

As discussed above the aim of this project was to review short break services understanding how they are commissioned and how they are provided. Due to limited information returned from a selection of providers, a desk-based review of short breaks provision across England was undertaken by parent-researchers. This section provides an overview of our findings. The review was undertaken from the perspective of parent-researchers who already had knowledge and understanding of short break services.

Understanding local short breaks provision.

The review established that the majority of local authorities (95%) did provide an explanation of what short breaks is for families of disabled children. However, one in ten did not have a dedicated webpage on their website and information was found to be on a website for a provider rather than the local authority. It was not uncommon for provider websites signposted to local authorities to be general websites, without a focus on short breaks.

The same proportion of local authorities did not provide information about the types of short breaks available for example, overnight respite or activity types and the criteria to attend short breaks was not provided. Therefore, it was not clear if short break providers listed covered particular age groups or what type of needs were accommodated. This supports findings from our interviews with parent-carers and freedom of information responses. This information is a basic requirement if parents are to have confidence in the services provided and make an informed choice about the type of service they can trust to support their disabled child safely.

There was a common theme for local authorities that did provide good information about short breaks to list the amount of hours available for families or include maximum hours that may be available. However, this implies services are not available in line with individual circumstance or needs of a family but via a pre-determined level of support.

Accessing short breaks

Findings from the earlier phase of this project established that parents of disabled children in need of social care support find themselves confronted by an information vacuum. Information is often not easily obtained and processes are not published in a transparent way, making it difficult for families to navigate. Our review looked at information available on the application process for short breaks and about the organisations responsible for providing short breaks.

However, one in four local authorities did not have information about the process to apply. Three in ten local authorities did not list the providers in their areas or signpost parents to provider contact detail for more information. For parents who may need more information from their local authority about short breaks, two in five local authorities did not provide a contact, corroborating what parents told us during their interviews.

It was felt it was common for local authorities to provide standard information about short breaks in the form of a duty statement, often stored on a pdf document rather than linked to the main website. Therefore, information could be found in some instances for parent carers with more experience of the system and the jargon that comes with it, but information was not provided in a standard way. Our review highlighted a serious concern for parents who do not have English as a first language. Just three in ten websites had an option to change the language or contained a flag or symbol to support parents with language needs.

Accountability of providers

During the interview phase of the project, parents told us about difficulties liaising with providers or withdrawing from provision as it did not meet their disabled child’s needs or they did not feel confident in the level of knowledge or expertise at the service. For parents who may experience issues whilst using short breaks, liaising with the local authority who commissioned the service should be an option. However, just a third of local authorities provided a direct contact at the local authority for this purpose. The lack of routes for parents to seek redress or discuss solutions to challenges when attending short break services, emphasises the lack of opportunity for the parent or disabled child’s voice to be heard or understood.

There is a lack of transparency about the process to access to short break services but also the support that disabled children and young people can expect to receive whilst attending.   Just one in four local authorities provided information about the costs of short breaks services on the websites, leaving parents with further administrative work to do to find this out directly from providers themselves.

Associated costs such as transport or food provision is also not readily available for parents to understand. Just one in six local authorities provided information readily the associated costs of short breaks.

As discussed above, information provided on websites for parents of disabled children about short breaks has the role of enabling parents to have confidence that their child will be supported and cared for in a safe and secure way that meets their needs. However, our review found that just one in eight local authorities provided information about how disabled children or young people would be supported.

The omission of information such as associated costs and how disabled children are supported at the provision means that the expectation of the service is not clear to families. As little information is available about what to expect, when families are faced with a service that fails to meet their disabled child's needs, clear routes for redress are not available and information about what should or should not happen are obscured from the parent perspective because of the lack of information readily available.

Conclusion

The aim of the phase of this project was to review the data available from local authorities about short breaks provision across England, to assess the equity of provision by ethnicity. Responses from local authorities, those with and without information on short breaks, highlighted a gap in the data collected about disabled children generally and raises concerns about how services are commissioned and monitored.

Local authorities are failing in their duty under the Children's Act 1989, to maintain a register of disabled children. The basis of a comprehensive figure for this group of children should mean that services can be monitored effectively to ensure they are commissioned in a way that meets disabled children's needs, not just arising from their disability but also by way of their age or ethnicity. However, local authorities were unable to tell us an overall number of disabled children or their ethnicity, in a way that could ensure the utilisation of services could be monitored in an effective way.

It was clear, as commissioners, local authorities were unable to report the types of short breaks available in the local area. Some responses referred to the inclusiveness of all services, stressing that all children could attend all universal services. Another common theme was to report that the local authority commissioned services on a need by need basis, however they were unable to report what those needs were. The lack of understanding of the needs of disabled children who require or use short breaks, present a serious problem when assessing outcomes services hope to achieve.

The earlier phase of our research included families describing provision that they could not use. Universal services accessible for disabled children are not sufficient for children with complex needs. Targeted support is required, provided by a workforce with the training, knowledge and expertise appropriate to give parents confidence that their children can be supported in a safe and secure way.

Parents of disabled children also told us that they welcomed opportunities to meet with families from the same ethnic background. However, responses from local authorities confirmed that none of the short break services were commissioned as targeted services by ethnicity. In addition, just a third of short break services can accommodate cultural needs of the families attending. Therefore, opportunities for meeting families from the same group are limited through current access to short breaks. The review of short break websites found that just three in ten websites had the option to select a language other than English, creating barriers in families without English as a first language in obtaining information about support available.

The review of short break providers, via website information reinforced our findings from the freedom of information responses and from parent interviews about an information vacuum. Lack of information or generic information leads to parent carers attending provision that does not meet their disabled child's needs. Withdrawing from short breaks, often on multiple occasions reinforces the feelings of isolation from others, with a negative affect on the families overall wellbeing.

The diversity of how information is presented about short breaks was evident during the review of local authority sites. Clarity is needed for families about the process, how support is provided, by what organisations and routes for redress should services fail to meet their disabled child's needs. Transparency and accountability is needed to ensure families can be confident in using short break services. Ensuring avenues are available for disabled children, young people and their parent's to be heard, will reduce families dropping out of the system, further marginalised and isolated from society.

Recommendations

The government should:

- Carry out an audit of local authority's registers of disabled children, and take action against those local authorities who are failing to meet their legal duty under the Children Act 1989 to maintain one.
- Work with local government and the disabled children's sector to address gaps in data on disabled children's services.
- Remind local authorities of their short break duties and review and re-issue the short breaks guidance, including lessons learnt from the Short Breaks Innovation Fund
- In doing so, pay particular attention to provision in the early years
- Include in the guidance specific advice on the support under the Care Act 2014 in respect of young people age 18-25 (and their families)

References

Children Act 1989 (legislation.gov.uk) paragraph 6

Advice template (publishing.service.gov.uk) -page 10