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Barriers to non-‘bed-based’ respite - final report

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Executive summary

Despite the availability of different options, the vast majority of respite care in Leeds for people with a learning disability and/or autism with moderate to complex needs takes place in bed-based settings. **The aim of this project has been to understand the actual or perceived barriers to non-bed-based respite and what can be done to overcome these barriers.**

A mixed-methods design was used to capture a '360 degree' view of barriers to non-bed-based respite. This included a literature review, postal survey with carers, semi-structured interviews with carers and relevant stakeholders, and consultation with service users via the Leeds Learning Disability People's Parliament.

Whilst the majority of carers felt they knew something about respite services in Leeds and that they could choose between bed-based and non-bed-based respite, **the default position for most carers, service users and stakeholders is that respite is a bed-based activity**, specifically in a residential facility.

Carers and service users highly value bed-based respite because of the benefits it brings, including the opportunity for service users and carers to have a 'break', for service users to socialise with peers, and for service users to learn independence. **Non-bed-based respite is not as well regarded and most carers would not want to use non-bed-based respite instead of bed-based respite.** Non-bed-based respite may have some appeal in facilitating service users to go on holiday.

Not wanting to lose bed-based respite, service users enjoying bed-based respite, fearing non-bed-based respite would not be enough of a break, and carers not knowing enough about non-bed-based respite appear to be the most prominent barriers to carers and service users not availing non-bed-based respite. Concerns about the inappropriateness of staff and venues was a prominent barrier to non-bed-based respite for carers of people with complex health problems and autism.

A number of suggestions for local and structural changes have been made about how respite services should be delivered in the future. Carers, service users and practitioners should be made more aware of the range of respite provisions available in the city. A 'menu' of available services and the opportunity to trial different services may allow carers to dispel any preconceptions about non-bed-based respite and make more informed choices. Information could be available from a central access point and from Care Managers and be accessible to all carers and service users.

Background and context

Respite care is the provision of short-term support to allow carers some relief from their caring duties and to help them continue caring (Box 1). The vast majority of respite in Leeds – circa 13,591 nights per annum – is currently in ‘bed-based’ placements. Leeds North Clinical Commissioning Group (CCG) and Leeds Adult Social Care expect the demand for respite to only increase, particularly from young people ‘transitioning’ from Children’s Services and from people with complex health needs and autism. As such, there is a need for the use of bed-based and non-bed-based respite to become more equitable.

Box 1: Respite care provision in Leeds

In Leeds, adults with a learning disability and/or autism and their carers are assessed as to their respite need. Those eligible work with a Care Manager to arrange the most appropriate respite. Choices include:

- Residential placements in local authority, NHS or third party managed facilities
- Community based respite, including a Shared Lives scheme where service users are cared for by somebody in the community
- One-off breaks, holidays and leisure activities in mainstream settings.

Respite services can be classified as either ‘bed-based’ or ‘non-bed-based’. Bed-based respite is when a service user is cared for away from home for one or more nights. Non-bed-based is when a service user is cared for by someone other than their usual carer – care may be overnight but in the service users own home. (In this instance, holidays are also considered non-bed-based respite).

The chosen respite activity is then funded by Leeds Adult Social Care and/or the NHS.

Alternatively, carers can chose to manage the cost of care themselves through a ‘Personal Budget’. This means they allocate the funding received by the person they care for themselves.

Leeds North CCG and Leeds Adult Social Care, Leeds City Council, have led a strategic review of respite services for adults with a learning disability and/or autism. There remains a need though to capture insight from service users, their carers and stakeholders around the primacy of bed-based respite.

The aim of this review is to **understand the actual or perceived barriers to non-bed-based respite for adults with a learning disability and/or autism with moderate to complex needs** and what mitigating factors can be put in place to counter concerns.

Specific objectives are:

1. Scope published literature for prior learning concerning the usage of non-bed-based respite for adults with a learning disability and/or autism with moderate to complex needs.
2. Identify levels of knowledge and awareness about respite services in Leeds, particularly alternatives to bed-based respite, among service users and carers,
3. Capture service user, carer and stakeholder perceptions of current respite in Leeds.
4. Understand the perceived or actual barriers towards non-bed-based respite and document any solutions.
5. Capture specific issues encountered by service users and carers in transition from Children's Services to Adult Social Care, including their respite aspirations for the future.

Achieving these objectives will inform more effective utilisation of capacity across the respite system in Leeds to cope with the increasing demand now and in the future.

Organisation of the report

This report is comprised of four sections. Firstly, a brief overview of the methodological approach to the review follows; this outlines the process by which the data was gathered and analysed. Existing knowledge in published literature concerning barriers to non-bed-based respite is then presented before moving on to discuss the findings of data collection. Finally, conclusions and recommendations are outlined.

Methodology

This section briefly summarises the methodological approach adopted for this review, including how data was collected and analysed.

The project sought to gain a ‘360 degree’ view of the barriers to non-bed-based respite for people with a learning disability and/or autism with moderate to complex needs in Leeds.

Drawing on qualitative and quantitative data in a mixed methods design allowed a rich understanding of carers and stakeholders lived experience to be triangulated against an overarching perspective, producing more substantive learning (Cresswell and Plano-Clark, 2011).

Literature review

Leeds Beckett University’s ‘Discover’ database was searched for published literature regarding barriers to non-bed-based respite for people with a learning disability and/or autism. **Eighteen relevant publications were identified and data extracted.**

Carers survey

A postal survey was the main data collection tool for assessing carers’ awareness of respite services in Leeds and the appeal of, and barriers to, non-bed-based respite (Appendix 1). This approach enabled a large number of carers to add their ‘voice’ to the project and provided an overarching perspective of carers’ understanding and perception of respite in Leeds (Bryman, 2012)¹.

127 completed surveys were returned out of 393 sent to carers (Box 2). A 32% response rate coupled with the distribution of respondents (Appendix 2) suggests the survey results may have some generalizability to other carers of people with a learning disability and/autism with moderate to complex needs who access respite in Leeds.

¹Leeds Learning Disability Community Support advised that carers may not understand ‘bed-based’ and ‘non-bed-based’ respite. As such, in the carers survey ‘residential’ and ‘non-residential’ were used as proxy terms for bed-based and non-bed based respite respectively. This decision appears justified as results of the data collection bore out carers’ perception of ‘residential’ and ‘bed-based’ as the same thing.

Box 2: Carers survey sampling procedure

'Learning Disability Community Support', 'Leeds Shared Lives' and the 'Joint Care Management Team (Learning Disability)' provided contact details of carers of current respite users.

Postal survey sent to 393 carers – along with information sheet and return envelope

127 completed surveys returned – 32% response rate

The survey also invited carers to be interviewed about their views and experiences of respite in more detail. 28 respondents indicated a willingness to take part.

Interviews

Semi-structured interviews illuminated the 'lived experience' (Savin-Baden and Major, 2013) of the barriers to non-bed-based respite. Interviewees were asked about their understanding of respite in Leeds, experiences of barriers to non-bed-based respite, and how respite could be improved (Appendix 3). All interviews were audio recorded. Participants unable to be interviewed face-to-face or over the telephone were invited to respond via email.

Carers initially volunteered to be interviewed at the end of the carer's survey. A random sample was then approached to take part. Stakeholders were purposively sampled by the project team based on their relevance to the project aims and objectives.

15 interviews were conducted, including **7 with carers of respite service users (CA)** and **8 with stakeholders (ST)** from Shared Lives, Learning Disability Care Management teams, Carers Leeds, Aspire, and other third sector organisations. It was not possible to interview any carers in 'transition'.

Service user consultation on the findings

An interim report, documenting the findings of the carers survey and semi-structured interviews, was presented at the Leeds Learning Disability People's Parliament on the 24th November 2014. The meeting was attended by around fifty people, including people with a learning disability (N≈38), advocates from Advonet (N≈7), and other presenters (N≈5). The majority of the people with a learning disability in attendance were current or ex- respite service users. Attendees were invited to comment on the results and were asked three specific questions: 'what is respite?', 'why don't people like non-residential respite?' and 'what should change in the future?'. Attendees worked in groups to discuss each questions and record their answers on a large piece of paper. The outcomes of the consultation are presented in this report as the voice of service users.

Data analysis

Interviews were analysed following a reflexive, iterative process. A common data extraction framework was devised based on key concepts pertinent to the projects primary objectives and populated with extracts from each interview. Results were then brought together and written up alongside the carer's survey results.

Quantitative data derived from the carer's survey was transferred to the computer programme SPSS. From there data was subject to appropriate descriptive and inferential statistical techniques.

Service user voice data from the consultation meeting with the People's Parliament was collated and analysed by the research team using the previously identified key themes as a thematic framework.

Literature review

Eighteen relevant publications, published between 1983 and 2011, were identified through the literature search. The publications were based on research carried out in the United Kingdom (n=9), the Republic of Ireland (n=6) and the United States of America (n=3). There are sufficient similarities, particularly in conceptualisations of, and policy responses to, learning disability and autism for research findings to be applied across these borders.

The publications are predominantly based on primary research (n=16), including surveys (n=6), qualitative methods (n=7), mixed methods (3) and a quasi-experimental design (n=1). Two publications draw on secondary research (i.e. literature reviews).

The aims of the identified research papers are diffuse. **No papers specifically examine the perceived or actual barriers to non-bed-based respite.** Rather, a common theme is the different experiences and outcomes of availing respite services more generally.

A number of papers (i.e. Power, 2009, Wilkie and Barr, 2008) focus on the experience of carers of children with a learning disability and/or autism. These papers are included in this review as they illuminate barriers to availing respite.

Purpose and importance of respite

Caring for someone with a learning disability and/or autism with moderate to complex needs can be stressful (Redmond and Richardson, 2003). The function of respite is to alleviate such stress and burden by providing a “temporary relief service” from the demands of continual caregiving (Cotterill et al., 1997, Mac Donald et al., 2007, Upshur, 1983:13, Wilkie and Barr, 2008). In doing so, respite provides carers a sense of renewal and confidence to continue caring; “a lifeline to [carers]...giving them the time and space to recharge their batteries” (Wilkie and Barr, 2008:30). It is the single most helpful service for families and, where not available, the most needed (McGill et al., 2006, Petr et al., 1991). Respite care can also benefit service users, encouraging the development of independence, facilitate a wide range of social opportunities, and offer the chance to become more involved in the community (Wilkie and Barr, 2008).

Power (2009) identifies the period immediately following the end of a child’s formal education as a particularly stressful time for carers (and service users) as special or mainstream schooling can no longer be relied upon for support or indirect respite. Despite its apparent importance, a lack of respite services during this ‘transition’ is a significant gap in provision (Power, 2009).

If delivered at inappropriate times, however, respite has little effect on relieving carers’ stress and burden (Cotterill et al., 1997). Moreover, whilst respite has been a significant enabler in the

historical transition from institutional to community care for people with a learning disability and/or autism (Mac Donald et al., 2007), respite should not be used to sustain placement at home which is inappropriate (McGrotherp et al., 1993).

Structure of respite

Different formats and structures of respite are described in the identified publications, including distinctions between 'in-home' and 'out-of-home' services (Cotterill et al., 1997) and residential care in specialist facilities and residential care in other, multipurpose facilities (i.e. hospitals, nursing homes) (Upshur, 1983). **In practise, however, 'respite' most commonly refers to service users staying overnight in a residential facility** (Wilkie & Barr, 2008; McConkey et al, 2011).

The literature suggests there is some desire for non-bed-based respite among carers and stakeholders. Wilkie and Barr (2008) highlight a desire for home-based support, including home-to-home schemes where people are cared for by another family in their home, and more leisure opportunities. Similarly, Cotterill et al. (1997) describe carers wanting more flexible short term provision, including part-day, weekend and evening services delivered in a family setting. The availability of non-residential respite varies, however. **In-home and community-care based respite are perhaps more likely to be available to children (Cotterill et al., 1997) and service users with lesser impairments and support needs** (Power, 2009).

Person centred planning

A strong theme in the identified publications is that respite services should be tailored to the needs of service users, not the state, and be delivered with a commitment to the family (Petr et al., 1991, Truesdale-Kennedy et al., 2006, Wilkie and Barr, 2008, HM Government, 2008, Mansell and Wilson, 2010). **A comprehensive range of respite services designed to meet a variety of family needs should be available to individual service users**, including ordinary holidays, family based respite, familiarisation services and services for people with challenging behaviour (Cotterill et al., 1997, Upshur, 1983).

'Person-centred care planning' is advocated to meet the individual needs of families. Carers appreciate a person-centred approach in identifying the particular needs of the person in their care and giving them a vision for the future (Truesdale-Kennedy et al., 2006). **Person-centred planning and flexible service provision is likely to become more important in the future as family structures change over time**, including more single parents, working mothers and less contact with extended family (Truesdale-Kennedy et al., 2006).

More emphasis on addressing individual family and service user need through “adopting a needs-led philosophy” is central to delivering a more cost effective service (Cotterill et al., 1997:785, McConkey et al., 2011). In order to meet the challenges faced by families, **public bodies should look to diversifying their offer, including working collaboratively with lay people and informal support networks** (Wodehouse and McGill, 2009).

‘Consumer directed care’ has arisen as part of the drive to give service users and carers more choice and flexibility in respite. Consumer directed care involves service users and carers controlling their own care budget and making choices about the services they access, including who will deliver the services and when. Consumer directed care allows users to source and manage services that match the unique needs of the people they care for (Redmond and Richardson, 2003). In some instances, consumer directed care can improve levels of satisfaction in families, increase carer employment, minimise out-of-pocket expenses, and reduce institutional placements (Caldwell, 2007, Redmond and Richardson, 2003). However, many service providers still exist in their own silos with little regard to the demands of service users (Power, 2009). Most research exploring the benefits of consumer directed care focuses on the experience of people with physical impairments (Caldwell, 2007). Equally, none of the identified research reported on the use of ‘direct payments’ or ‘personal budgets’ in the UK.

Barriers to respite services

That parents and carers may face a number of barriers preventing access to potentially beneficial respite services was a clear theme in the identified literature. Power (2009:97) describes an ‘implementation gap’ between political rhetoric regarding service provision and largely “cosmetic on the ground” services. This has created a scenario where carers felt services were lacking in both availability and quality (Power, 2009), and that service providers frequently failed to understand carers’ reticence to avail themselves of services that might be of value (Mansell and Wilson, 2010).

Lack of information

The availability of useful information is vital to the sustainability of families as carers (Redmond and Richardson, 2003). Yet **the most significant barrier to availing respite concerned the difficulty of accessing relevant and comprehensive information about services** (Cotterill et al., 1997, Redmond and Richardson, 2003, Wilkie and Barr, 2008).

The process of gaining information is haphazard, with carers often referred to speak to different officials and receiving conflicting information (Redmond and Richardson, 2003, Power, 2009). Carers instead rely on informal networks, including friends, family, other contacts and the internet (Redmond and Richardson, 2003, Wodehouse and McGill, 2009).

A centralised service (i.e. a telephone line) may be an effective method for providing carers with information, advocacy and support to avail essential services, including respite (Redmond and Richardson, 2003). Dedicated project staff or volunteers to support carers may also make accessing respite easier (Truesdale-Kennedy et al., 2006). However, the apparent information deficit may be a “smokescreen for the service users” to cover the gap between the aims of ambitious political programmes and limited resources to fund them properly (Power, 2009:94-95).

Eligibility

Restrictive eligibility criteria prevents access to respite (Cotterill et al., 1997, Redmond and Richardson, 2003). The most prominent example of not ‘fitting’ inclusion criteria related to challenging behaviour (McGill et al., 2006), with carers of people exhibiting serious challenging behaviour very often not receiving adequate support. Age may also be a factor (Redmond and Richardson, 2003), with some services only available to users of a given age.

Exclusion from respite forces carers to either purchase appropriate services themselves or go without (Redmond and Richardson, 2003).

Time and location

Physical and temporal barriers to respite limit carers availing of services. A lack of “regular, reliable and continuous support” was described (Wilkie and Barr, 2008, Wodehouse and McGill, 2009:651). Respite offered when service users already attend a regularly scheduled event was inappropriate (McGill et al., 2006, Wilkie and Barr, 2008). This was particularly the case for respite offered during the day.

With regard to location, respite delivered locally is highly valued by carers (Cotterill et al., 1997, Redmond and Richardson, 2003, Wilkie and Barr, 2008). Although most carers face difficulties relating to the availability of appropriate services in their local area, a dearth of local services is most keenly felt in rural areas (Redmond and Richardson, 2003).

Admin/bureaucracy

Administrative delays and bureaucracy in the organisation of respite adds to the strain of caring for someone with a learning disability and/or autism, and provides a barrier to accessing services (Redmond and Richardson, 2003). Supportive and understanding attitudes from providers and flexibility in delivery are crucial in meeting service users’ requirements (Power, 2009).

It is not only carers and service users who find systems confusing, however. A lack of clarity about responsibilities can be inherent in the organisational structures of service providers (Redmond and Richardson, 2003).

Guilt and worry

Feelings of guilt, embarrassment and increased stress can prevent carers from utilising respite (Cotterill et al., 1997, Hartrey and Wells, 2003, Wilkie and Barr, 2008). Redmond and Richardson (2003) report mothers feeling a strain or worry when their child was in an environment with children with different needs. Other carers worry their use of respite indicates an inability to cope (Mac Donald et al., 2007).

Negative emotions associated with respite often ease after a short period of time (Wilkie and Barr, 2008). Feeling happy and confident in a service allays carers' feelings of guilt and anxiety, enabling them to benefit more from the break (Cotterill et al., 1997). **Reducing the stress associated with respite also occurs by having regular respite in the carer's home and establishing a long-term relationship with a particular respite care provider** (Hartrey and Wells, 2003).

Inappropriate venue/staff/service

Carer perception of the appropriateness of respite may play a crucial role in determining whether or not families avail of services (Mac Donald et al., 2007). Carers experience anxiety about the perceived quality of provision (Cotterill et al., 1997, Wodehouse and McGill, 2009, Mac Donald et al., 2007, Caples and Sweeney, 2011), including

- The suitability of the environment and facilities
- The reliability of the service
- The knowledge, training and competency of staff
- Lack of rapport between service users and staff
- Service users in an environment alongside people with different support needs

These barriers are **most keenly felt by those with complex medical needs or challenging behaviour**.

Human capital and personal characteristics

Availing of respite services may relate to the personal characteristics of carers. Carers who are tenacious in their pursuit of services and more articulate middle-class families with financial and psychological resources may be more likely to succeed in accessing appropriate respite (McGill et

al., 2006). Family size and the availability of social support networks may not affect the likelihood of a family using respite (Mac Donald et al., 2007).

Cultural and religious

Carers from ethnic minority backgrounds underuse community care and respite services compared to other ethnic groups (Dura-Vila and Hodes, 2009, McGrother et al., 2002). It is a myth, however, that people from minority ethnic communities have lower levels of need for respite services (McGrother et al., 2002).

Carers from minority ethnic backgrounds are less likely to be aware of respite services and are **more likely to encounter additional barriers preventing them availing of services**. Social, cultural and religious values and beliefs about the cause and concept of 'learning disability' may result in the underutilisation of respite (McGrother et al., 2002). Concerns also exist about a lack of culturally appropriate diet, facilities for washing and purifying, and language needs within respite (Cotterill et al., 1997, Dura-Vila and Hodes, 2009, McGrother et al., 2002). As such, carers from minority ethnic communities may be more inclined to express a need for family-based respite (Cotterill et al., 1997).

Gaps in the literature

There are gaps in the evidence base regarding barriers to non-bed-based respite for adults with a learning disability and/or autism with moderate to complex needs.

- Foremost is the dearth of research specifically exploring the experience of, and barriers to, availing non-bed-based services as oppose to barriers for accessing 'respite' more generally.
- It also appears that service planning and provision is made – consciously or unconsciously – in accordance with 'white' norms, with a lack of accessible information and knowledge sharing with minority ethnic communities. It is critical that service providers and future research examine culturally based assumptions about caring and the needs of minority ethnic communities.

Limitations of this review

Given the resources, it was not our intention to conduct a full systematic review of the barriers to non-bed-based respite care for adults with a learning disability and/or autism with moderate to complex needs.

Our search of key academic databases uncovered no papers reporting specifically the barriers to non-bed-based respite. This could mean that a more comprehensive search of published and grey literature would have uncovered further work.

Notwithstanding this, this review has captured learning and outcomes concerning barriers to availing of respite services. These points of learning are transferable and will be discussed later in the report.

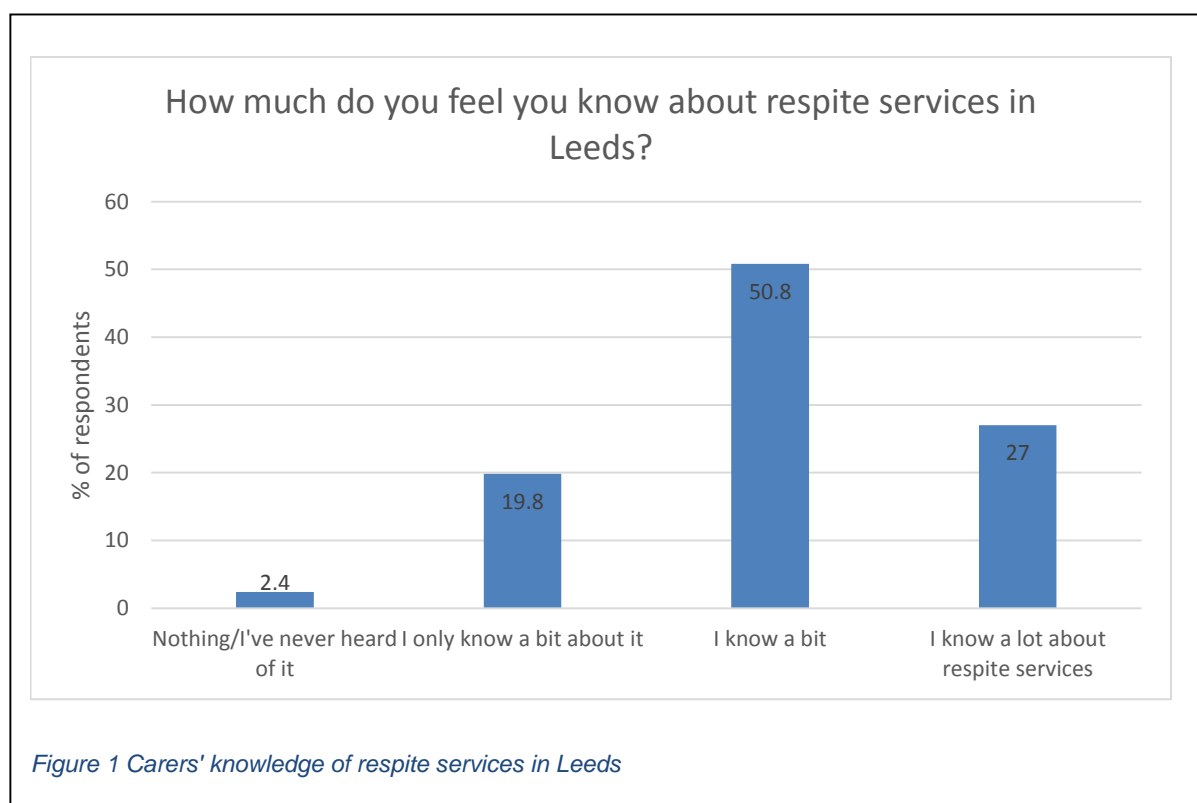
Findings

This section brings together data gathered across the carers' survey, interviews with carers and stakeholders, and from the People's Parliament consultation to address the pre-defined objectives of the project: 1) knowledge and awareness of respite services in Leeds; 2) perceptions of current respite provision; 3) perceived or actual barriers to non-bed-based respite; and 4) aspirations for future respite care.

Where relevant, reference is made to supporting or contradictory findings from the identified research literature.

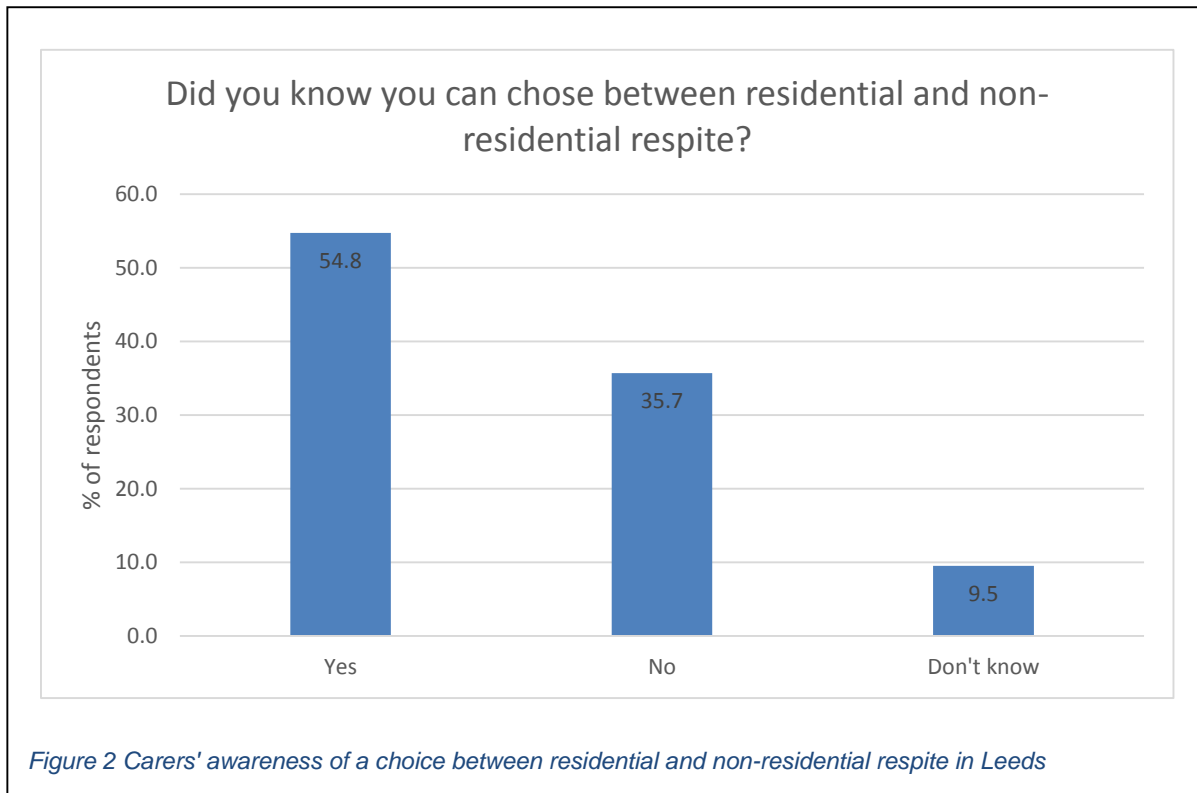
Knowledge and awareness about respite services in Leeds

Previous research suggests a lack of knowledge and awareness of respite services among carers (Cotterill et al., 1997, Redmond and Richardson, 2003, Wilkie and Barr, 2008). The situation in Leeds appears to be mixed (Figure 1).



27% respondents to the carers survey feel they know 'a lot about respite services' in Leeds, whilst 50.8% feel they know 'a bit', 19.8% feel they 'only know a bit' and 2.4% feel they know 'nothing/have never heard of respite'.

Spearman's Rho^2 tests revealed a small positive correlation between how much information carers felt they had about respite and their age ($r=.202$, $n= 126$, $p <.05$) and the age of the person they care for ($r=.252$, $n=126$, $p<.01$). A Mann-Whitney U^3 test also revealed a small negative correlation between how much information carers felt they had about respite and ethnicity ($z=-2.156$, $p=.031$, $r=-.196$). This suggests that **older carers, carers of older service users and carers from white-British backgrounds feel they have more information about respite services in Leeds**. No other relationships were observed.



Just over half of respondents (54.8%) know they have a choice between residential and non-residential respite, whilst over a third (35.7%) do not (Figure 2). A Mann-Whitney U test revealed a small positive correlation between how knowledgeable respite services carers feel and their awareness of a choice between residential and non-residential respite ($z=-2.503$, $p=.012$, $r=0.235$), with **more knowledgeable carers slightly more aware of a choice**.

However, as in the identified publications, **the “default position” (ST3) for most carers, stakeholders and service users is to conceptualise ‘respite’ as a bed-based service**.

² Spearman's Rho is a non-parametric test to describe the strength and direction or the linear relationship between two variables.

³ Mann-Whitney's U is a non-parametric test to assess the difference between two independent groups on a continuous variable.

Moreover, carers and many stakeholders understand respite to mean bed-based respite **specifically in a residential facility**. Service users were also generally not aware of a distinction between bed-based and non-bed-based respite.

Carers and stakeholders recognised that “a break from caring” (ST4) can be achieved through non-bed-based activities. One stakeholder described the “creative...things people do and call it respite” (ST5). However, non-bed-based activities are not generally considered to be respite; “it would be [the service users] social needs being met...not their respite needs” (ST3).

Perceptions of current respite care provision in Leeds

Carers and stakeholders have some grievances about respite in Leeds. Carers of people with complex autism particularly felt respite was not able to meet the need of the person they care for. Overall, though, carers generally thought respite in Leeds was “very good”, with most carers “quite happy with how things are going” (CA3). However, **such positivity is a reflection of bed-based rather than non-bed-based respite**.

Bed-based respite was described as “essential” (ST1), a “lifeline” (ST1) and “a God send” (CA3) for carers. **A number of factors contribute to the importance of bed-based respite** (Box 3).

Non-bed-based respite was not viewed as positively, nor does it have the same appeal, as bed-based respite. 55.3% of respondents thought non-residential respite was not appealing, with 39% stating that non-residential respite was ‘not appealing at all’ (Figure 3).

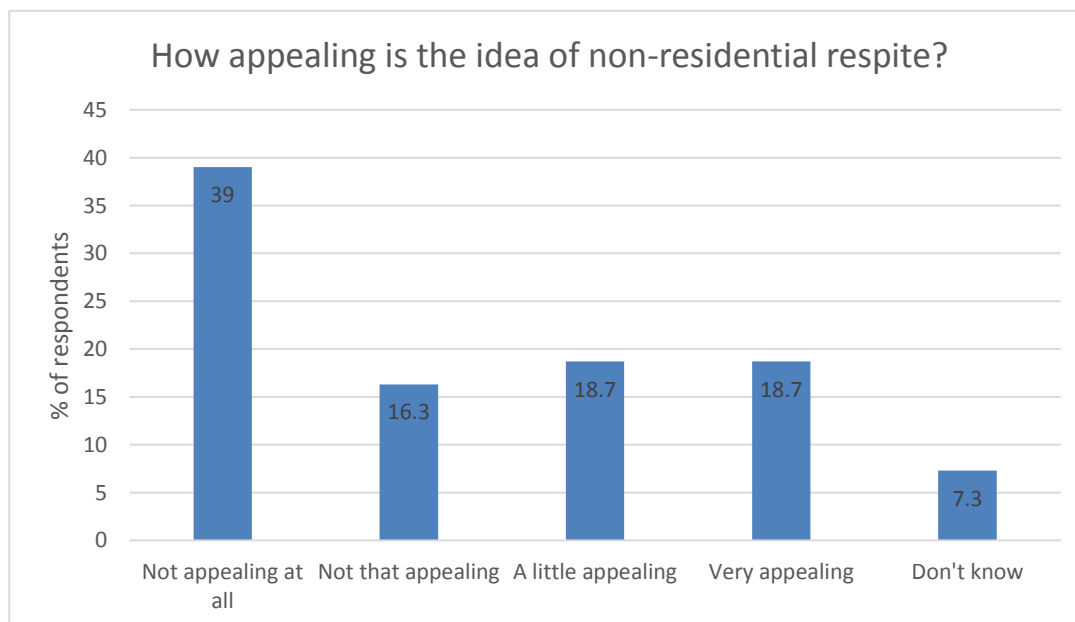


Figure 3 The appeal of non-residential respite

Box 3: Why is bed-based respite so important?

- **A break from caring.** Bed-based respite provides carers with a “break” (CA1) from the otherwise “24 hour responsibility” (CA2) of caring.
- **Family time.** Bed-based respite provides an opportunity for carers and their families to do “things that are difficult when you are caring” (ST4)

‘Usually it’s just nice to relax at home’ when son is in respite. Son ‘talks a lot’ – ‘it’s just nice to sit down with everybody else and not have to think. Not to be on guard all the time... We often sleep better... That I don’t have to get up – it’s such a treat.’ (CA5)

- **Free time.** Bed-based respite provides carers with an opportunity to do what they want, including “very ordinary things” (ST4) such as going to the supermarket.
- **Preserving families.** Family units “take a hard knock” (CA5) caring for an adult with a learning disability and/or autism. Bed-based respite relieves “a great deal of...stress” (ST1) within families.
- **A suitable environment.** For most carers, bed-based respite facilities are regarded as “very well equipped”, capable of dealing with service users’ complex needs and “challenging behaviour” (CA5).
- **Service users have a break.** Bed-based respite also provides service users with an opportunity to have a “holiday away from their carers” (ST1) and experience a different setting.
- **Enjoyable for service users.** Bed-based respite was thought of as an enjoyable experience for service users.
- **A chance to socialise.** Bed-based respite was thought of as “quite a social thing as well” (ST5), enabling service users to “mix with other people” (CA6). Carers often try and arrange bed-based respite at times when the same service users will be attending in order to build up continuity.
- **Activities.** Bed-based respite includes a chance for service users to do activities they otherwise would not.

“If I’m at home with him on my own, I might think, ‘I just can’t be bothered today. And if you’re happy sitting there watching television or playing with something and doing something himself, I’m quite happy to do that today, because I haven’t got the energy to take you out...” (ST4)

- **Learn skills and take risks.** Whilst service users can be “overprotected” in their family environment (ST2), bed-based respite allows service users to take risks and try new things.
- **Gain independence.** Bed-based respite challenges service users to adapt to being around other people in a new social and domestic environment. Crucially, it gives service users a “taste of supported living” (CA4), which was particularly important to carers concerned about planning for the future when they are no longer able to continue in their caring role.

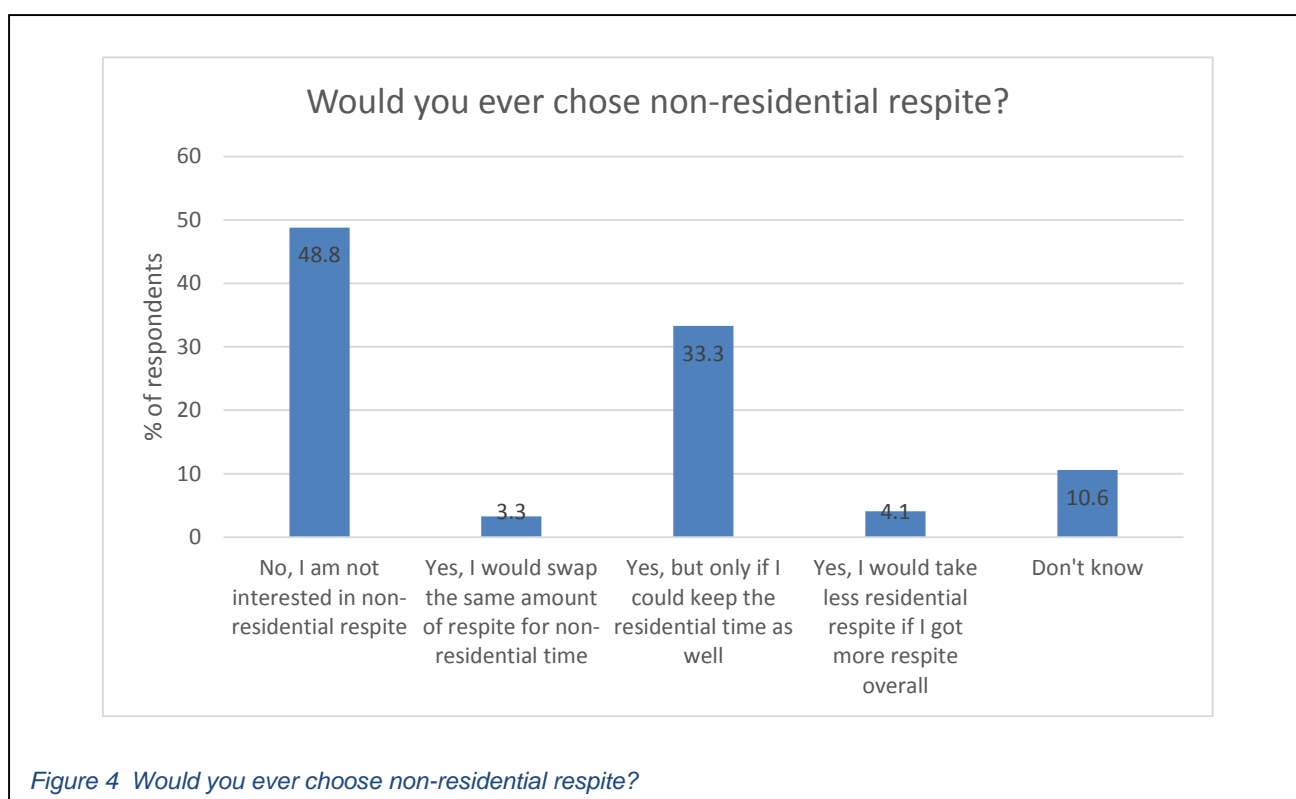
“It’s about teaching him independence and about him learning to live a different life away from us as well. Because we’ve always recognised that at some point [son] is going to need full time residential care” (CA5).

A Spearman’s Rho test found a small negative correlation between the appeal of non-residential respite and both the age of carers ($r=-.207$, $n=108$, $p<.031$) and the age of the person they care for

($r=-.254$, $n=113$, $p<.007$). This suggests that **as carers and the people they care for age non-bed-based respite becomes slightly less appealing**. No other correlations were identified.

48.8% of survey respondents would not consider non-residential respite (Figure 4). Although almost 40% of respondents said they would choose non-residential respite, only 3.3% would do so as a direct alternative to residential respite. Most (33.3%) would only do so in addition to their current residential provision. A smaller number (4.1%) indicated that they would give up some residential respite time in exchange for a greater amount of non-residential respite time. **This suggests that non-bed-based respite might be appealing as an adjunct to bed-based provisions.**

No relationships were observed as to who would chose non-residential respite.



Interview respondents suggested carers would consider non-bed-based respite “in an emergency situation” (Q), such as if they were unwell and unable to perform their caring role. **Non-bed-based respite may also have some appeal enabling service users to go on holiday** (Box 4).

Box 4: Non-bed-based respite as a holidays for service users

Many carers want the person they care for to have the opportunity to go on holiday. Whilst some carers have been able facilitate this themselves, holidays can be troublesome, with the cared-for person getting bored and wanting to do different activities to their carers.

‘We’re fuddy-duddies for him now. He doesn’t mind doing some things with us, but he likes to do things with other people.’ (CA5).

Using respite time to allow a cared for person to go on holiday was welcomed; “instead of just going to a home they might be able to go on a holiday” (CA4).

A holiday would be especially appealing if the cared for person was able to go with “somebody that [they] know” (CA4).

Although there are options available to enable a cared for person to “go on holiday for the first time” (ST2) (i.e. Shared Lives, Direct Payment), carers are not aware of these in great numbers.

The appeal of Direct Payments

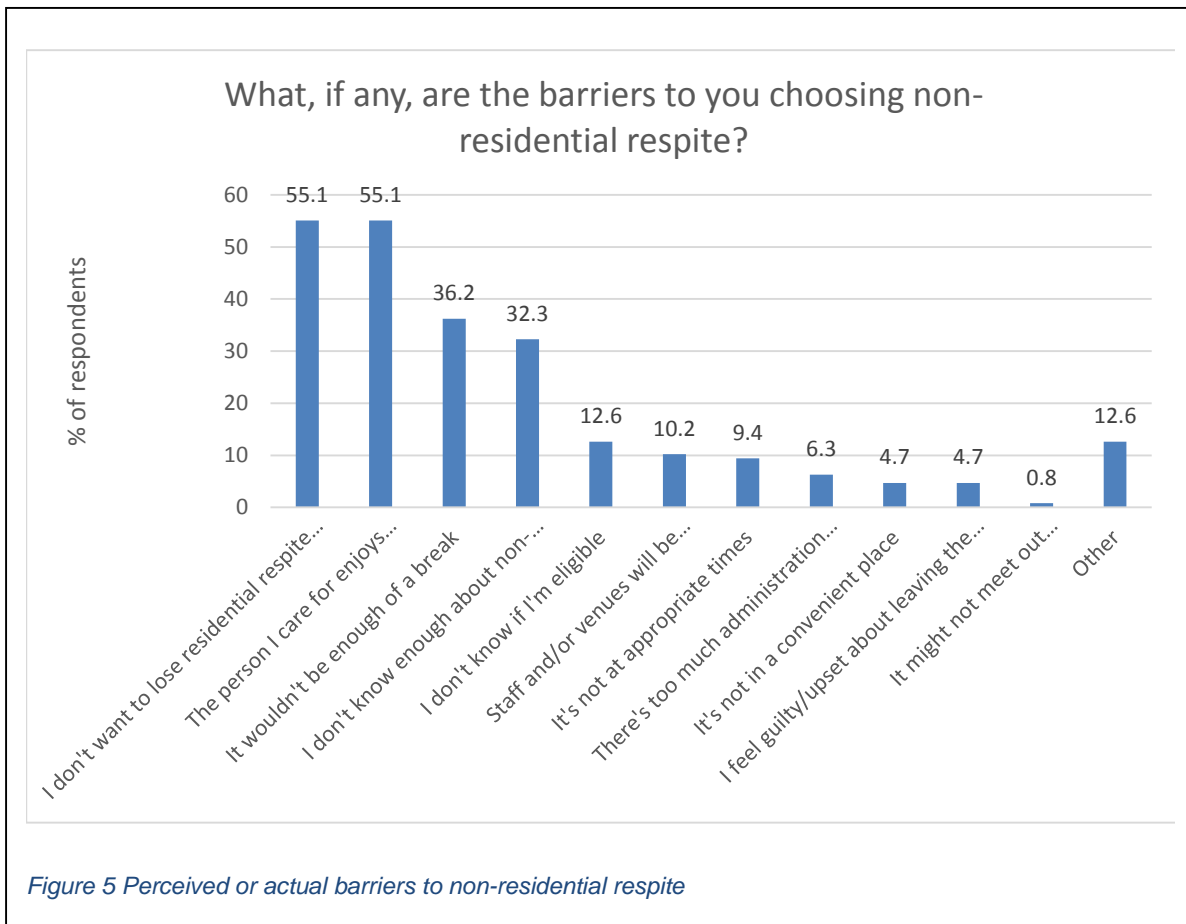
Direct Payments are promoted as a way for families to source and manage services that match their unique needs, thereby improving their satisfaction with services, minimise costs, and reduce institutional placements (Caldwell, 2007, Redmond and Richardson, 2003). In Leeds, Direct Payments were described as an opportunity for carers to be “creative” (ST5) with the services they access, including “more flexibility in how they want their respite to be provided” (ST3).

The perception of Direct Payments among carers, however, was generally negative. One carer said their use of Direct Payments in the past was “one of the worst things that ever happened” to their household (CA2).

Direct Payments were criticised for being too “complicated” (ST2) and creating more work for carers. Utilising Direct Payments was viewed as “doing Leeds City Council’s work for them” (CA2). Whilst carers want a choice regarding respite, they “have got enough on their plate” (ST2) coping with the caring responsibilities.

Perceived or actual barriers towards non-bed based respite.

A number of perceived or actual barriers to carers availing non-bed-based respite were observed in the carers survey (Figure 5) and during interviews with carers and stakeholders.



'I don't want to lose bed-based respite'

55.1% of respondents indicated a fear of losing their current residential respite allocation. As highlighted previously, **bed-based respite is highly valued by carers and the thought of not having it is extremely troubling for carers.**

A Mann-Whitney U test revealed a small statistically significant difference between carers highest academic qualification and not wanting to lose residential respite as a barrier to availing non-bed-based respite ($p=0.015$, $n=27$, $r=-.212$). This indicates that **those with higher academic qualifications were more likely to see losing bed-based respite as a barrier.**

'The person I care for enjoys bed-based respite'

An equally significant barrier was that **service users enjoy bed-based respite**; 55.1% of respondents reported this was the case. One questionnaire respondents said "my daughter loves her stay at residential and treats it as a holiday".

Service users suggested that **attending bed-based (residential) respite was an enjoyable activity**; something they looked forward to doing. The enjoyment mostly stemmed from bed-based

respite being an opportunity to socialise, to take part in activities and for service users to have a break from their families.

There is a danger, however, that services users' preferences for particular services has a detrimental effect on carers, preventing them availing the most appropriate services to support them in their caring role.

"Sometimes the barrier is the cared for person not wanting to accept the support that the carer would like - doesn't like the look of the place, the look of the people, or just thinks 'I want you to do everything for me'. That can be a barrier" (ST4).

'It wouldn't be enough of a break'

Just over a third of survey respondents (36.2%) felt that non-residential respite would not provide them enough of a break from their caring responsibilities. Bed-based respite provides a "proper break" (Q) from caring responsibilities, whereas **carers felt non-bed-based respite would not allow them to "get away completely" (CA4), physically and emotionally.**

This view was shared by service users who suggested **residential respite was an opportunity for service users to have a break from their parents.** Service users felt this may not be achieved in non-bed-based respite.

'I don't know enough about non-bed-based respite'

32.3% of survey respondents felt that a lack of information was a barrier. A Mann-Whitney U test indicated a small statistically significant difference between carers' stated awareness of respite services and seeing lack of information as a barrier. This indicates that **those with more awareness of respite were less inclined to view a lack of information as a barrier to availing non-bed-based respite.**

Service users also felt they did not know enough about non-bed-based respite. Some suggested that, given more information, they would be open to trialling non-bed-based.

Accessing information about respite services in Leeds is "really difficult" (ST4) for carers. Carers felt there is "not enough" (CA1) information available and what little information is available is "dotted around" (CA1) at different locations.

Carers rely on care professionals to help them make sense of their options regarding respite services. However, there remains "a lot of ignorance" (ST5) among care professionals in Leeds regarding different respite services; many are not aware that respite has "more to offer than

buildings based” residential respite (ST2). As such, **bed-based residential respite dominates the offer.**

Many **carers rely on informal networks or word-of-mouth for information** regarding respite; “other people in a similar situation...are the best people to find out things from” (ST4). It appears that **the experience of other families can be very powerful in both creating and dispelling misconceptions** about respite services in Leeds.

It appears that **carers and care professionals “probably don’t know enough about any non-residential respite”** (ST7). The Shared Lives scheme, for example, according to these findings, is not well known amongst carers or care professionals. Misconceptions about Shared Lives are persistent barriers. It was felt that Shared Lives is not part of individual or strategic “discussions” about respite across the city (ST2). As such, carers “don’t know what to do and how to access [different respite services]” (ST3).

‘I don’t know if I’m eligible’

12.6% of respondents reported not knowing if they were eligible for non-residential respite.

In accordance with the identified research literature, **age is a significant factor with regard to perceived eligibility.** Carers felt that their choice of a different respite services “disappear[s] off the radar” (CA2) once service users reach adulthood. One stakeholder suggested non-bed-based respite “feels like something for a younger service users” (ST3).

Perceived **eligibility also extends to how well a family is judged to be coping in their caring role.** That is to say, families not in ‘crisis’ – “if you’re classed as a competent family” (CA5) – are thought to need less support from care professionals and will therefore be less able to access different services, including non-bed-based respite.

‘Staff and/or venues will be inappropriate’

For just over a tenth of survey respondents (10.2%), concerns that staff or venues for non-residential respite will be inappropriate for service users is a barrier. This concern was also expressed by service users.

“As a carer you have to feel that the provision is good in order for you to relax and enjoy that time away from caring.’ If you think the person is not going to be happy then you’re not going to take it up other than in an emergency”. (ST4)

There is a **concern that non-bed-based respite will take place in a venue which is not suitable to the individual needs of service users.** Concerns include:

- **Staff at non-bed-based respite being less competent**, including a “lack of specialist medical knowledge” (Q), and less reliable than those in bed-based residential settings.
- **Service users being cared for in non-bed-based respite alongside inappropriate service users**; some service users need to be with other service users with the same “specific needs” (CA2) – medical and social – whilst others thrive in a more mixed environment.
- **Non-bed-based respite being ‘unsafe’** compared to bed-based respite which are perceived as having “more safeguards in place” and “proper routines [and] regulations” (CA5).

Concerns about inappropriate staff and venues are **exacerbated for carers of adults with more complex health needs, challenging behaviour and autism.**

“When it comes to autistic people, you need someone with a good knowledge of the actual person and a good knowledge of autism... There has to be a good understanding of this complex condition. What might fit one person, won’t fit another.” (CA7)

Comparatively, bed-based respite in a residential setting is viewed “like a really good hotel” that understands the complexity of service users (ST3).

‘It’s not at appropriate times’

9.4% of respondents reported non-residential respite not being at appropriate times as a barrier.

Carers want the flexibility to avail respite when it suits their needs. For example, some carers want to have respite at weekends, whilst others like to spend that time with the person they care for – “she goes away through the day anyway, why bother having it at weekend as well” (CA3).

However, **carers perceived non-bed-based respite as being very inflexible and only during weekdays.**

Non-bed-based respite is also viewed as unreliable; support workers may be unavailable for a short time or move on to other roles. Many carers are concerned about longer term consistency in the services they receive and bed-based respite care, particularly in a residential setting, “feel[s] more stable” (ST4).

‘There’s too much administration/bureaucracy’

6.3% of respondents suggested that accessing non-residential respite involved too much administration and/or bureaucracy.

This does not mean availing non-bed-based respite involves too much administration and/or bureaucracy per se, **rather it involves too much administration and/or bureaucracy for carers already “used to [bed-based] services” (ST7)**. For carers already stretched by their caring responsibilities, availing non-bed-based respite equates to “somebody else to have to meet with, something else to have to organise” (ST4). It’s simpler to think “my life’s complicated already, I’m not going there” (ST4) and remaining just with bed-based respite.

Additional administration and/bureaucracy can also be a barrier to care professionals, particular for Care Managers who liaise with carers. In the “fast, furious life of a Care Manager, [needing] results quickly and...to move onto the next situation,” (ST2) the time and effort to discuss and arrange anything other than bed-based respite is a disincentive to promoting non-bed-based respite to carers. A lack of time to facilitate non-bed-based respite was described as a “structural” barrier (ST2).

‘It’s not in a convenient place’

4.7% of respondents reported non-residential respite not being in a convenient place as a barrier.

One questionnaire respondent stated that non-bed-based respite would be more appealing “if it was somewhere local to where we lived” (Q). Another carer did not want the person they care for attending non-bed-based respite because they thought it would take place in what they perceived as “very nasty little area[s]” of the city (CA7).

‘I feel guilty/upset ‘

4.7% of respondents reported that feelings of guilt or upset caused a barrier.

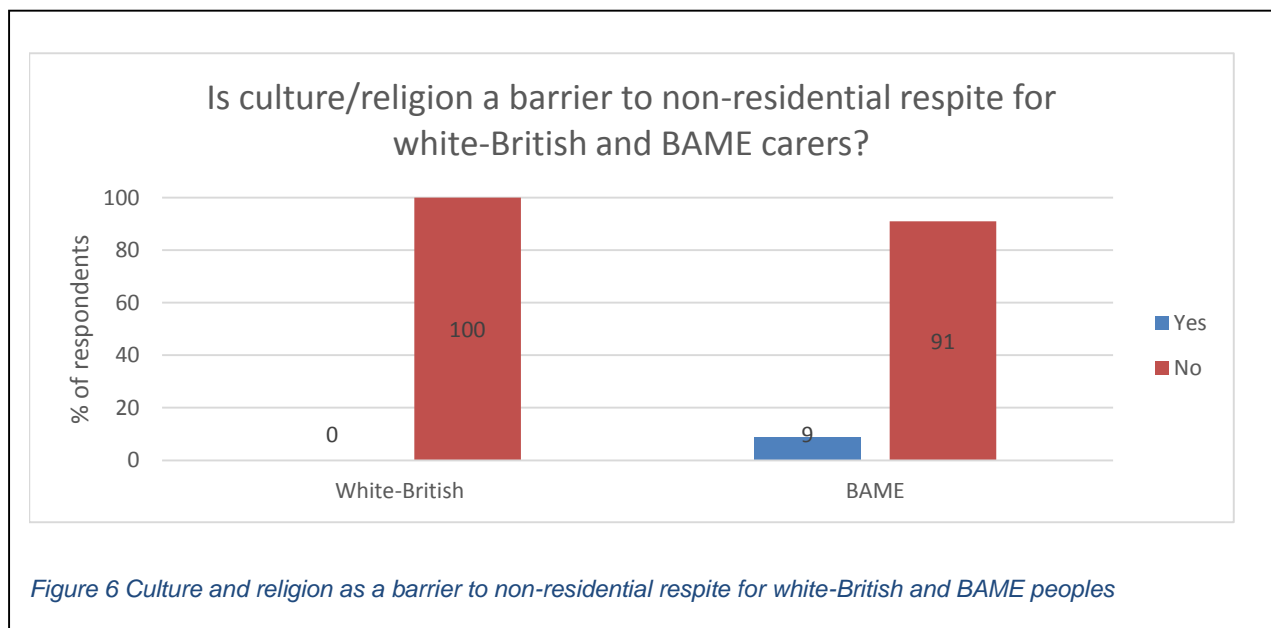
Mirroring the identified literature, accessing respite can cause carers to feel guilty and anxious that they have “failed” in their caring role (ST4) or that they “always should be there for the child with disability” (CA5). As such, utilising **non-bed-based respite was thought to be “not worth the upset for the short time you receive” (Q)**. Moreover, some forms of non-bed-based respite, such as community-based care, may exacerbate negative emotions because of a view that “if that family can cope...why can’t I?” (ST2).

‘It might not meet our cultural needs’

Only 0.8% of respondents indicated a concern that non-residential respite would not meet their cultural or religious needs was a barrier.

A comparison between respondents from white-British and Black, Asian and minority ethnic (BAME) backgrounds (Figure 6) suggests **cultural or religious differences are not a significant**

barrier to carers from BAME backgrounds in Leeds. This contradicts the assertion of the identified published literature. However, this may be a response bias as a result of the limited number (n=11) of survey respondents from BAME communities.



'Other'

12.6% of respondents suggested another barrier prevented them from availing non-residential respite.

- **Carers may already have their non-bed-based respite needs fulfilled**, either through purchasing additional support from “outside agencies” (Q) or because the person they care for attends other scheduled activities.
- **The ‘human’ capital of carers – their knowledge, skills and capacities – was alluded to as a barrier to availing non-bed-based respite.** ST3 suggested how “creative” respite is depends on “the demanding nature of the family” and that “some families are better [at availing personalised services] than others”.
- Carers were also concerned that **non-bed-based respite would be prohibitively expensive.**
- **Non-bed-based respite may breach the privacy of carers and their families;** “being able to trust people in your home” (Q) is a barrier. Service users also expressed concern that non-bed-based respite may feel like “they’re being invaded by strangers”.

“You can have respite in your own home. If you wanted to go on holiday ... somebody would come into your home and work there 24 hours a day. The issue with that is not a lot of people take that up because it’s someone coming into your home that you don’t know and you’re not there.” (ST5)

Carers and service users in transition & aspirations for future respite provision

The identified publications suggests that the transition from children's to adult service is a significant time for carers and service users with regard to availing respite services (Power, 2009). For example, on completion of a child's formal education, carers can no longer rely on school to provide support or indirect respite. Appropriate respite services during this time of transition is considered a significant gap in provisions (Power, 2009).

It was not possible to include the voices of carers in transition in this project. However, one stakeholder described shortcomings of the process in Leeds. They alluded to **a stark contrast between children's and adult services in terms of provisions and environments**. For example, one young service user liked to play with children's toys but "those things disappear completely in adult respite" because of a view that "adults don't play with toys" (ST4). As such, it became apparent that the service user "didn't fit easily into what was available in adult services" (ST4).

The stakeholder also suggested that **the transition phase does not start early enough**.

How should respite be delivered in the future?

Carers, stakeholders and service users suggested how respite should be delivered in the future (Box 5). Whilst a number of suggestions relate to modifications of bed-based residential respite, they may have broader application. **Carers and service users also stressed that they would not like to see bed-based residential respite being stopped**.

It would appear that many carers and service users do not fully understand the range of respite services in Leeds or labour under misconceptions about non-bed-based provisions. **More information about different respite services would be beneficial in helping carers and service users make more informed decisions**. Carers and service users need information that is "really clear...something that spells out what is available" (ST4), including examples of what different people do and the combination of provisions that are possible.

"To be able to go to and say 'this organisation does it this way and that little group does it that way, it's not just the six buildings around the city'" (ST3)

An accessible "menu" (ST2) of provision would enable carers and service users to make informed choices about respite. This may involve working closely with third party providers to publicise non-

bed-based respite. A “flow chart” (ST2) of different respite options may also help Care Managers see beyond ‘traditional’ bed-based respite.

The option to ‘trial’ different respite services may also facilitate carers and service users utilising provisions other than traditional residential respite. Currently there appears to be a lot of confusion and apprehension about non-bed-based respite.

Box 5: How respite should be delivered in the future

- **Personal relationships** – service providers and practitioners should get to know service users and their families. This includes having “named support” throughout respite and a “passport of how to support the individual” (ST8)

“It’s a person-centred approach that’s needed. Not a fancy building. Not everything laid on. It’s the person liking the other person” (CA7).

- **Meeting the needs of carers and service users** – there is sometimes an assumption that “if the needs of the cared for person are being met...the needs of carers are being met” (ST4). This is not the case.
- **Social activity** – Respite should provide opportunities for service users to engage in social activities, including romantic interactions where appropriate. Practitioners should coordinate with one another in order for service users to do things together.
- **Flexibility, Creativity, Choice** – Respite provisions need to “work to the requirements of the service user” (ST1), including ‘bespoke packages’.

“They might say, ‘if you don’t want the full week, split the week and just have a night here and there. I’d like to see that’” (CA6).

- **A respite ‘market place’** – the provision of a range of respite services is improving in Leeds. However, a market place “isn’t well developed” (ST2). Service users and carers need to be more aware of their options.
- **Collaboration** – The local authority should work more closely with third sector organisations able to provide appropriate provisions for service users. One Carer, for example, said the Leeds Autism Service was “very good” and “should receive more funding...so that they could do more” (CA7).
- **Teaching independence** – respite can be a tool to help service users “learn to be away from home” (CA5). This is particularly important for older service users and carers concerned about future planning.
- **Overnight stays** – whether in a bed-based residential setting or community care, overnight respite allows carers to have a “break completely” (CA1).
- **More activities** – for many service users, respite provides opportunities to engage in meaningful activity – “no point in them going and just sitting there” (CA3). Providers should plan a programme of activities around the interests of service users and keep carers informed of what they are doing.
- **Staff** – having a “core team” (ST3) is an attractive feature of bed-based residential respite. Sufficiently qualified, long term staff should be in place across all provisions.
- **Volume** – of course, the option of “more would be nice” (CA1)

Conclusions and issues for consideration

This project has aimed to understand the actual or perceived barriers to non-bed-based respite for adults with a learning disability and/or autism with moderate to complex needs in Leeds.

Results suggest that the majority of carers feel they have at least some knowledge of respite care in Leeds and are aware of a choice between bed-based and non-bed-based, with carers feeling more knowledgeable with age. However, the 'default position' for most carers, service users and, in some cases, health and care practitioners, in Leeds is that respite is a bed-based activity in a residential facility.

Bed-based respite is viewed as beneficial for carers and service users. Of particular importance are the social connections service users make during residential stays and a belief that bed-based respite enables service users to prepare for when carers are no longer able to continue in their caring roles and of living away from home. This positive view does not extend to non-bed-based respite. Most carers would only utilise non-bed based respite as an adjunct to their bed-based provision. Non-bed-based respite may have some appeal to carers and service users, however, as an opportunity for service users to go on holiday.

The most frequently cited reasons for carers and service users in Leeds not availing of non-bed-based respite are:

- Not wanting to lose bed-based respite
- Service users enjoying bed-based respite
- Non-bed-based respite not being enough of a break
- Not knowing enough about non-bed-based respite

Other reasons include concerns about not being eligible, inappropriate staff and/or venues, bed-based respite not being at convenient times or in convenient locations, too much administration/bureaucracy, carers feeling guilty or upset, non-bed-based respite not satisfying cultural or religious needs, the 'human capital' of carers to access services, cost, carer already accessing a proxy non-bed-based respite and non-bed-based respite breaching privacy of carers and families.

For service users and carers 'transitioning' between children's and adult social care in Leeds, limited evidence suggest the process may be too abrupt.

A number of suggestions for local and structural changes have been made about how respite services in Leeds should be delivered in the future. Most significantly carers, service users and practitioners should be made more aware of the range of respite provisions available in the city. A 'menu' of what is on offer, including examples of who has used the service in the past and where

services can be personalised, and the opportunity to trial different services may help to dispel some misconceptions about non-bed-based respite and allow carers to make more informed choices about the services they access. Information could be available from a central access point and from Care Managers and be accessible to all carers and service users. Work should be done collaboratively with third party providers to ensure choice.

Limitations

A mixed methods design has been used to capture a '360 degree' view. This included a literature review, postal survey of carers, semi-structured interviews with carers and relevant stakeholders, and consultation with service users. One stakeholder reflected on their experience of working with carers transitioning between children's and adult social care. However, it has not been possible to include first-hand the voices of carers in 'transition'. As such, it is not possible to describe carers' in transitions' perception of non-bed-based respite or to say what those just entering the social care system for adults with a learning disability and/or autism in Leeds will want from respite in the future. Future work should look to address this deficit. Further investigation into the experiences and perceptions of carers from BAME communities may also be beneficial.

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Respite care in Leeds



This survey is for carers. It is about residential and non-residential respite care.

Residential respite is where the person you care for spends the night away from home being looked after.

Non-residential respite is where they are looked after but **do not** stay overnight. This covers a range of things, including the person you care for being looked after at home while you go out, them taking part in supported leisure activities or going on holiday.

Q1 How much do you feel you know about respite services in Leeds?

- Nothing at all/I've never heard of it.....
- I only know a little bit
- I know a bit
- I know a lot about respite services.....

Q2 Do you know you can choose between residential and non-residential respite?

- Yes.....
- No
- Don't know

Q3 How appealing is the idea of non-residential respite to you?

- Not appealing at all
- Not that appealing
- A little appealing
- Very appealing
- Don't know

Q4 Would you ever choose non-residential respite care?

- No, I am not interested in non-residential respite.....
- Yes, I would swap the same amount of residential respite for non-residential time
- Yes, but only if I could keep the residential time as well
- Yes, I would take less residential respite if I got more respite overall
- Don't Know.....

Q5 What, if any, are the barriers to you choosing non-residential respite? (please tick all that apply).

- I don't want to lose residential respite hours
- I don't know enough about non-residential respite
- I don't know if I'm eligible
- The person I care for enjoys residential respite
- It's not at appropriate times
- It's not in a convenient place
- There's too much administration involved
- I feel guilty/upset about leaving the person I care for
- Staff and/or venues will be inappropriate
- It might not meet our cultural/religious needs
- It wouldn't be enough of a break
- Other

If 'other', please specify



Please turn over

Q6 What would make non-residential respite more appealing to you?

We would also like to gather some personal information to help us compare your answers to other people. It will be **completely confidential and anonymous**.

Q7 How old are you?

- | | |
|------------------------------------------|--------------------------------------------------|
| Less than 18 .. <input type="checkbox"/> | 51 - 60 <input type="checkbox"/> |
| 18 - 30 <input type="checkbox"/> | 61 - 70..... <input type="checkbox"/> |
| 31 - 40..... <input type="checkbox"/> | 71 + <input type="checkbox"/> |
| 41 - 50..... <input type="checkbox"/> | Prefer not to say <input type="checkbox"/> |

Q8 Do you care for more than one adult who is eligible for respite care?

- Yes.....
No
Prefer not to say

Q9 How old is the person (people) that you care for?

- | | |
|--------------------------------------|--------------------------------------------------|
| 18-20 <input type="checkbox"/> | 51-60 <input type="checkbox"/> |
| 21-30 <input type="checkbox"/> | 61+ <input type="checkbox"/> |
| 31-40 <input type="checkbox"/> | Prefer not to say <input type="checkbox"/> |
| 41-50 <input type="checkbox"/> | |

Q10 How much care & support would you say this person needs? (If more than one person, how much care and support do you feel you provide overall?)

- Constant care & support.....
Most of the time
Some of the time
Very little care & support.....
Prefer not to say

Q11 How is caring responsibility divided?

- I am the sole/primary carer.....
Caring is shared with another person(s) in the same household.....
Caring is shared with another person(s) outside the household
Prefer not to say.....

Q12 How would you describe your ethnicity?

- White British.....
Asian or Asian British (Indian).....
Asian or Asian British (Pakistani)
Asian or Asian British (Bangladeshi).....
Asian or Asian British (Chinese).....
Black or Black British.....
Mixed or multiple
Other ethnic group.....
Prefer not to say.....

Q13 What is your highest academic qualification?

- No academic qualifications.....
GCSE or O Levels
Practical qualifications (i.e. HND, BTEC)
A Levels.....
Foundation degree.....
University degree.....
Postgraduate qualifications
Prefer not to say.....

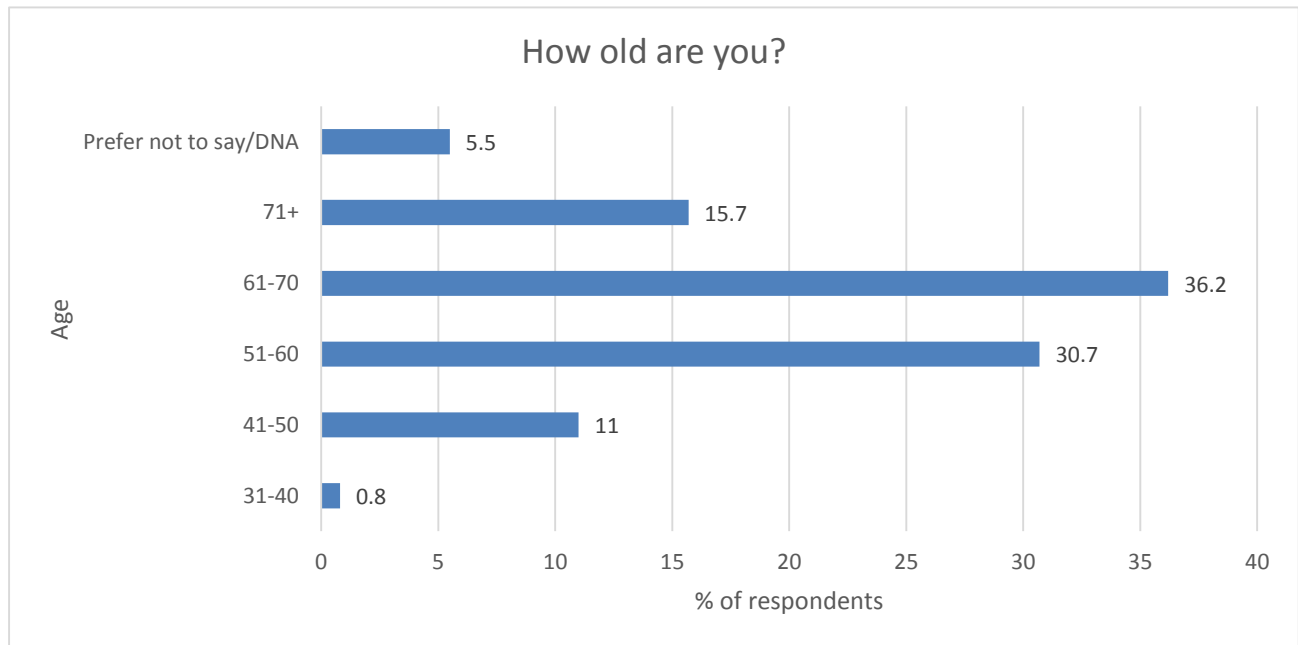
If you would like to be interviewed please provide your name and daytime telephone number. This **information will be confidential**.

Please return completed survey in the enclosed envelope by 14/8/2015

Appendix 2: Carers survey respondents

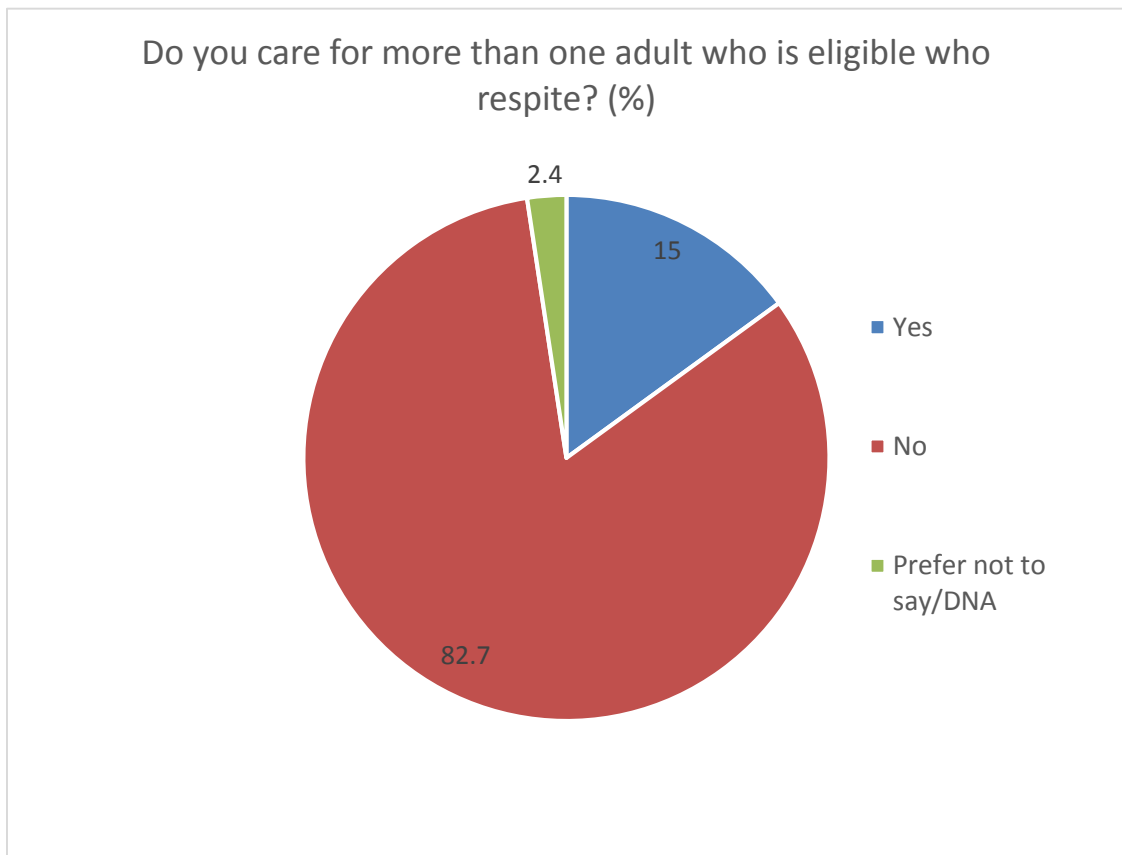
Age of respondents

| Age | Frequency | Percent | Cumulative frequency |
|-----------------------|------------|------------|----------------------|
| 31-40 | 1 | 0.8 | 0.8 |
| 41-50 | 14 | 11.2 | 12 |
| 51-60 | 39 | 31.2 | 43.2 |
| 61-70 | 46 | 36.8 | 80 |
| 71+ | 20 | 16 | 96 |
| Prefer not to say/DNA | 5 | 4 | 100 |
| Total | 127 | 100 | 100 |



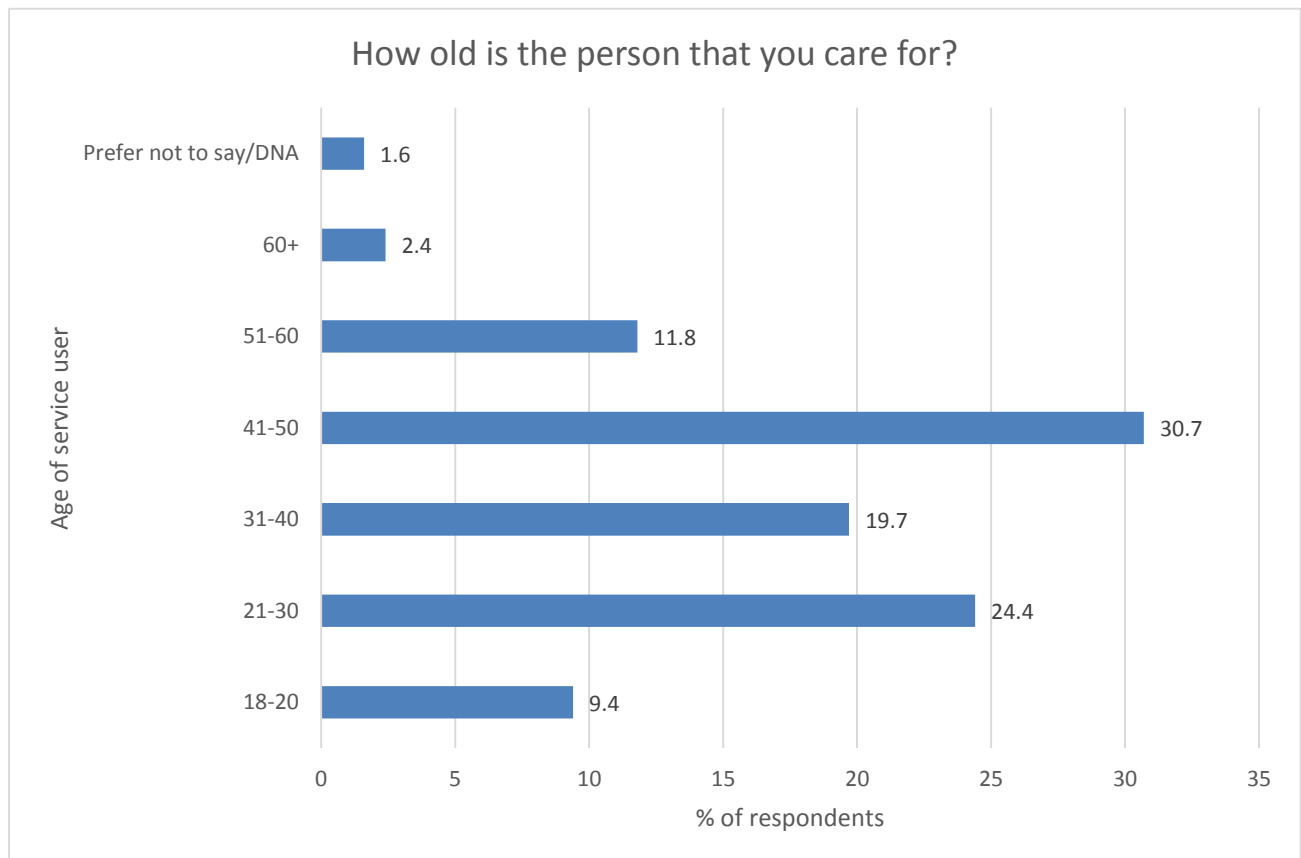
Do you care for more than one person?

| | Frequency | Percent | Cumulative percent |
|-----------------------|-----------|---------|--------------------|
| Yes | 19 | 15 | 15 |
| No | 105 | 82.7 | 97.6 |
| Prefer not to say/DNA | 3 | 2.4 | 100 |
| Total | 123 | 100 | 100 |



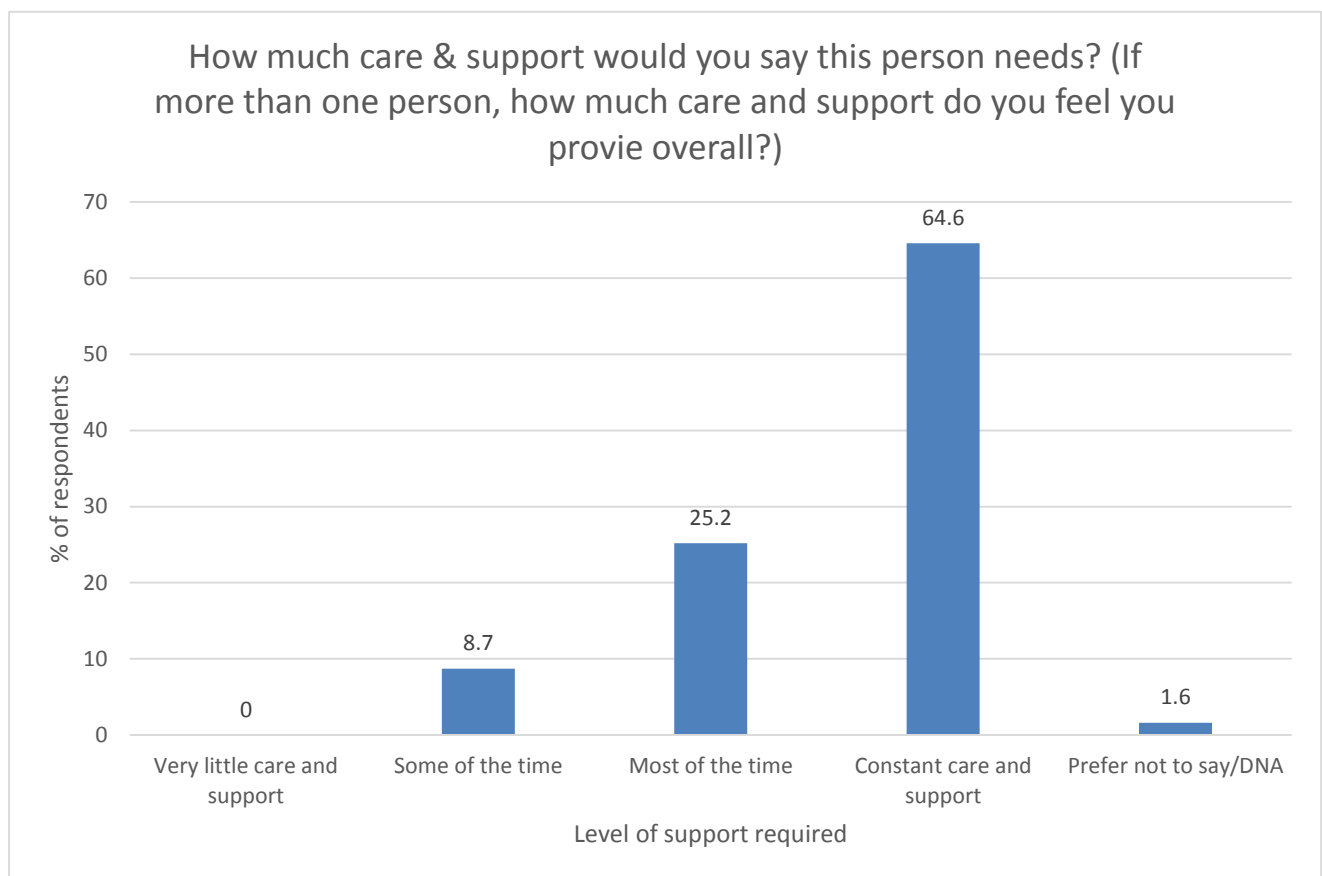
Age of service user

| Age | Frequency | Percent | Cumulative percent |
|-----------------------|------------|------------|--------------------|
| 18-20 | 12 | 9.4 | 9.4 |
| 21-30 | 31 | 24.4 | 33.9 |
| 31-40 | 25 | 19.7 | 53.5 |
| 41-50 | 39 | 30.7 | 84.3 |
| 51-60 | 15 | 11.8 | 96.1 |
| 60+ | 3 | 2.4 | 98.4 |
| Prefer not to say/DNA | 2 | 1.6 | 100 |
| Total | 127 | 100 | 100 |



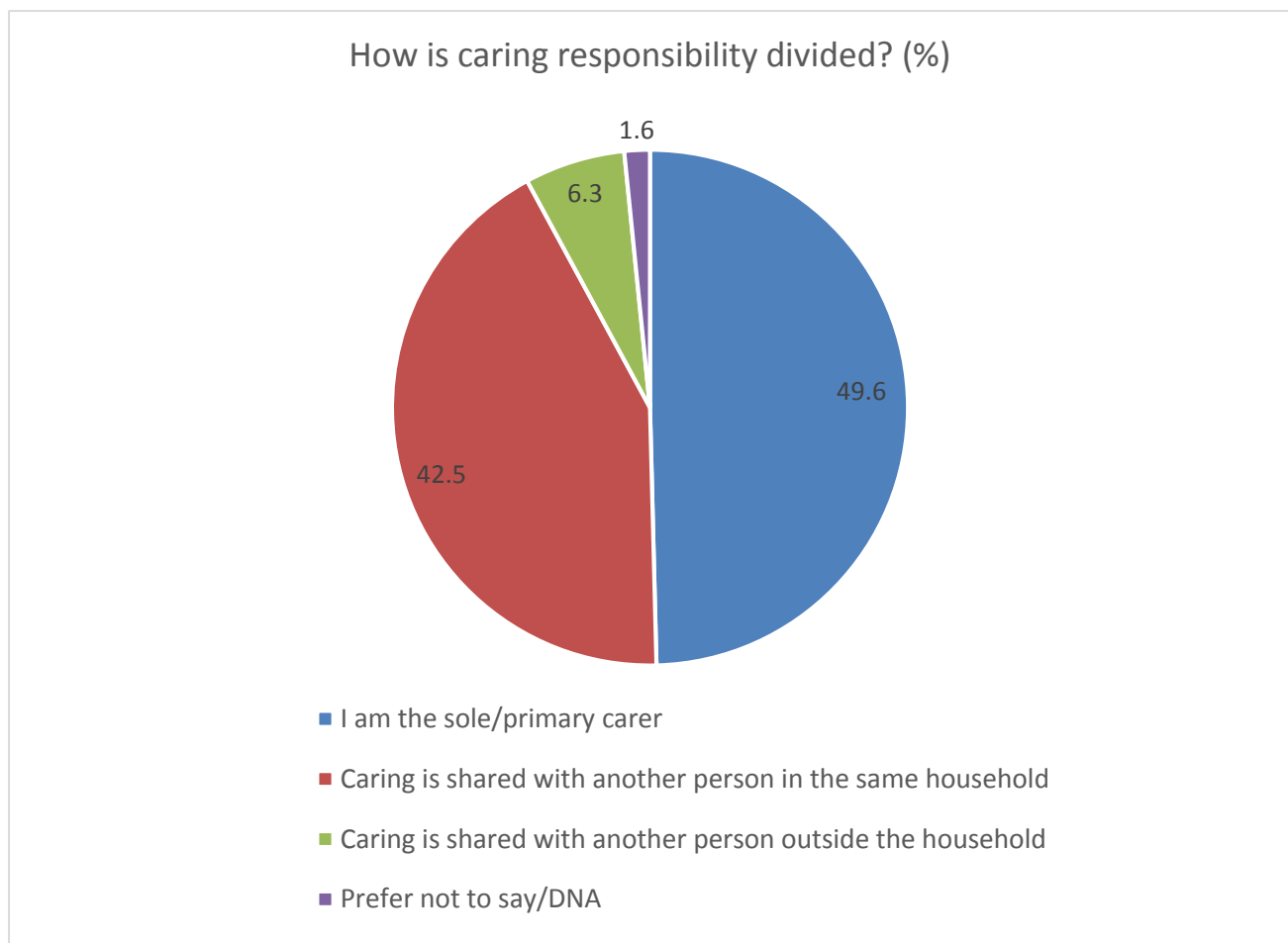
Amount of care needed

| | Frequency | Percent | Cumulative percent |
|------------------------------|------------|------------|--------------------|
| Very little care and support | 0 | 0 | 0 |
| Some of the time | 11 | 8.7 | 8.7 |
| Most of the time | 32 | 25.2 | 33.9 |
| Constant care and support | 82 | 64.6 | 98.5 |
| Prefer not to say/DNA | 2 | 1.6 | 100 |
| Total | 127 | 100 | 100 |



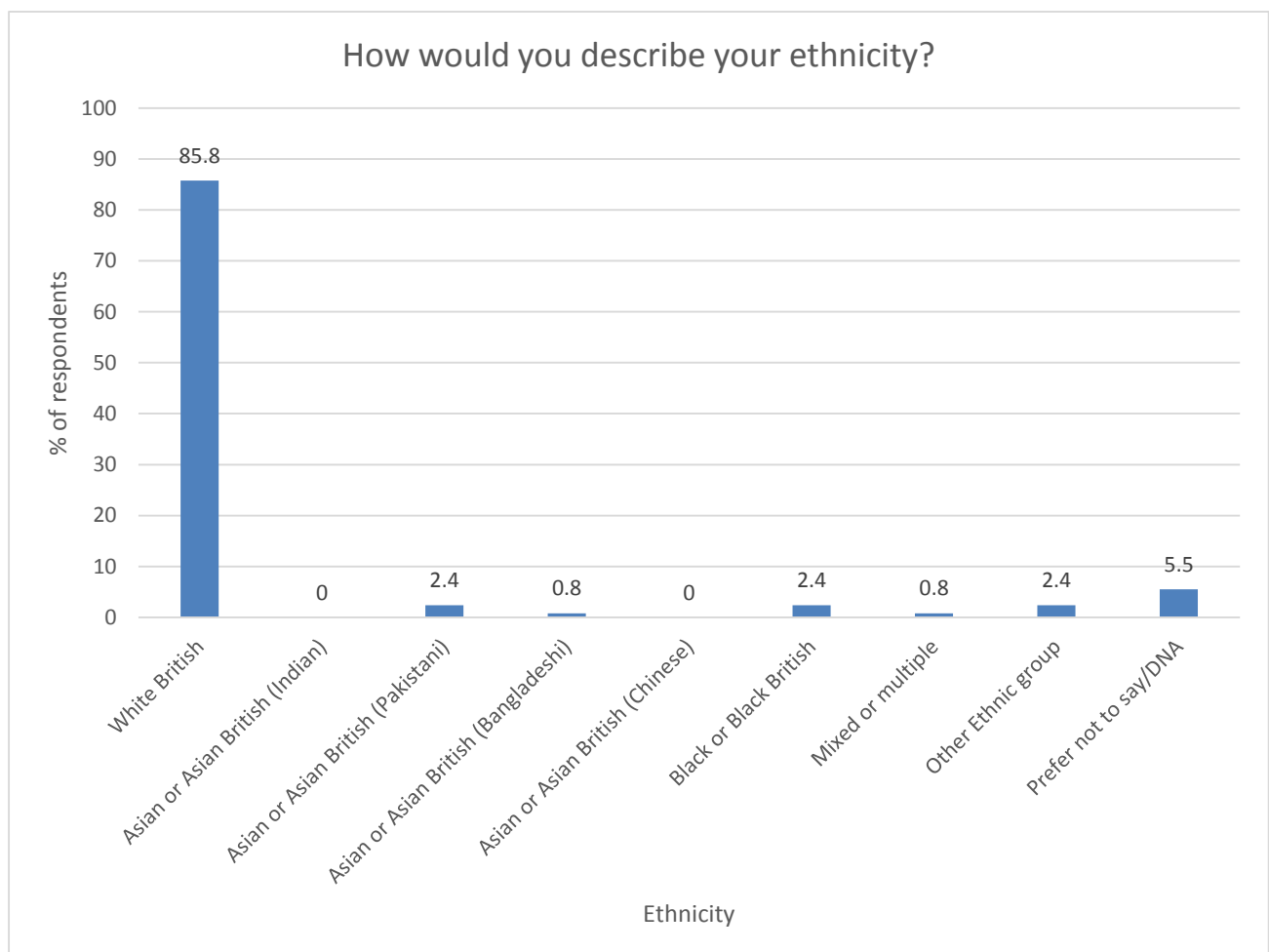
Caring responsibility division

| | Frequency | Percent | Cumulative percent |
|------------------------------------------------------------|------------|------------|--------------------|
| I am the sole/primary carer | 63 | 49.6 | 49.6 |
| Caring is shared with another person in the same household | 54 | 42.5 | 92.1 |
| Caring is shared with another person outside the household | 8 | 6.3 | 98.4 |
| Prefer not to say/DNA | 2 | 1.6 | 100 |
| Total | 127 | 100 | 100 |



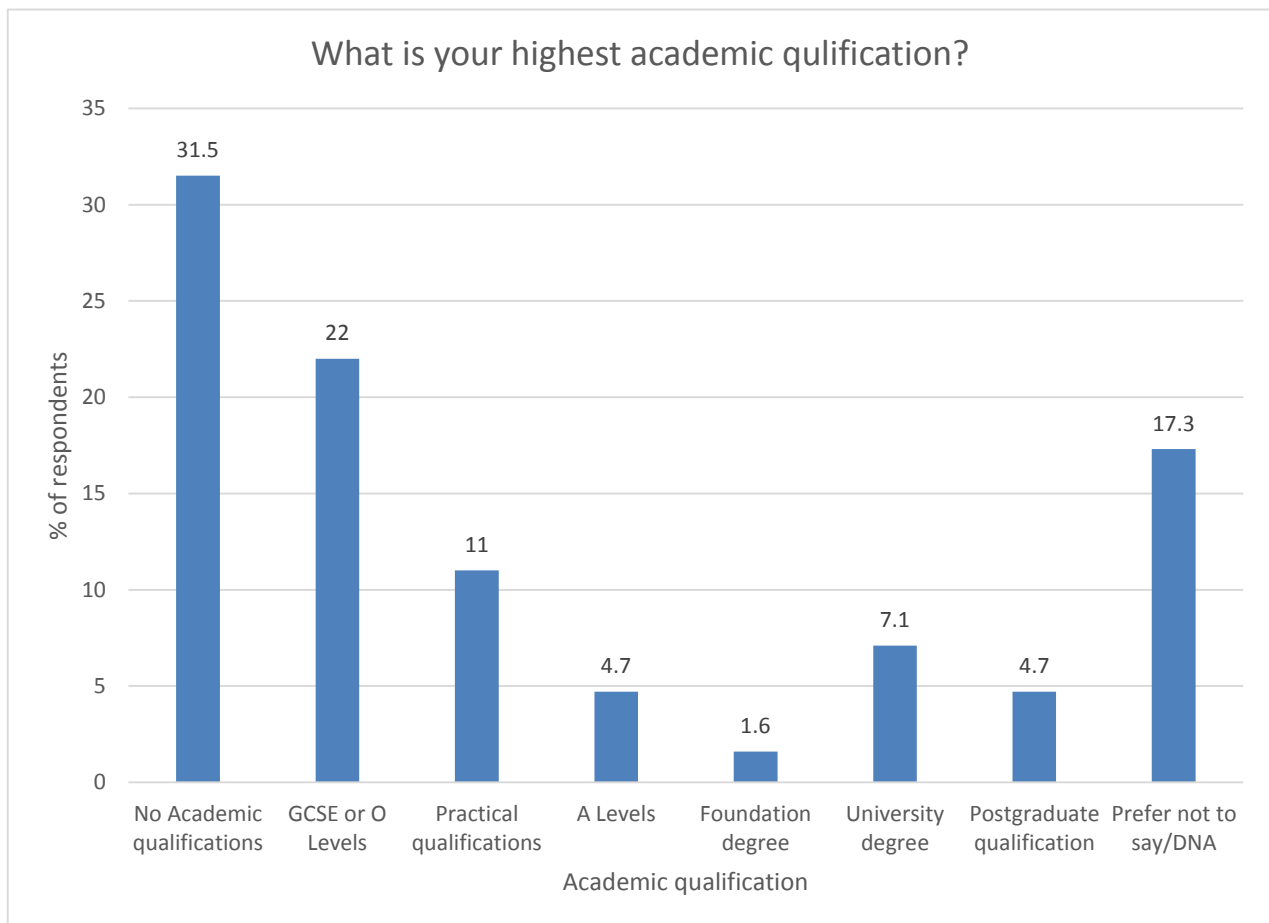
Ethnicity

| Ethnicity | Frequency | Percent | Cumulative percent |
|--------------------------------------|-----------|---------|--------------------|
| White British | 109 | 85.8 | 85.8 |
| Asian or Asian British (Indian) | 0 | 0 | 85.8 |
| Asian or Asian British (Pakistani) | 3 | 2.4 | 88.2 |
| Asian or Asian British (Bangladeshi) | 1 | 0.8 | 89 |
| Asian or Asian British (Chinese) | 0 | 0 | 89 |
| Black or Black British | 3 | 2.4 | 91.3 |
| Mixed or multiple | 1 | 0.8 | 92.1 |
| Other Ethnic group | 3 | 2.4 | 94.5 |
| Prefer not to say/DNA | 7 | 5.5 | 100 |
| Total | 127 | 100 | 100 |



Academic qualifications

| Qualification | Frequency | Percent | Cumulative percent |
|----------------------------|------------|------------|--------------------|
| No Academic qualifications | 40 | 31.5 | 31.5 |
| GCSE or O Levels | 28 | 22 | 53.5 |
| Practical qualifications | 14 | 11 | 64.6 |
| A Levels | 6 | 4.7 | 69.3 |
| Foundation degree | 2 | 1.6 | 70.9 |
| University degree | 9 | 7.1 | 78 |
| Postgraduate qualification | 6 | 4.7 | 82.7 |
| Prefer not to say/DNA | 22 | 17.3 | 100 |
| Total | 127 | 100 | 100 |



Appendix 3: Interview schedules

Carers

1. Can you tell me about your experiences of respite?
2. What is your understanding of respite and how it operates?
 - a. Different types of respite care
3. From your experience, in what ways does respite support people?
 - a. How does it support carers?
 - b. How does it support service users?
4. Are there any barriers to accessing respite care?
 - a. Personal barriers (i.e. not convenient times)
 - b. Systemic barriers (i.e. services not available)
 - c. Particular barriers to non-residential respite
5. Are there any ways that respite provision could be improved or modified to better support people?
 - a. Particularly non-residential
6. Are there any aspects of respite that are particularly important that should be maintained long term?
7. Do you have any recommendation about how you would like respite to be delivered in the future?
 - a. Particularly non-residential respite?

Carers in transition

1. Can you tell me about your experiences of respite?
2. What is your understanding of respite and how it operates?
 - a. Different types of respite care
3. From your experience, in what ways does respite support people?
 - a. How does it support carers?
 - b. How does it support service users?
4. Do you think there are any barriers to accessing respite care?
 - a. Personal barriers (i.e. not convenient times)
 - b. Systemic barriers (i.e. services not available)
 - c. Particular barriers to non-residential respite
5. Are there any aspects of respite that will be particularly important?
 - a. The outcomes you would like to achieve
 - b. How respite is delivered
6. How would you like to see respite delivered in the future?
 - a. Particularly non-residential respite?

Stakeholders

1. Can you tell me about your role in respite care?
2. Can you tell me how respite operates?

- a. Different types of respite care
- 3. From your experience, in what ways does respite support people?
 - a. How does it support carers?
 - b. How does it support service users?
- 4. Do you think there are any barriers to accessing respite care?
 - a. Personal barriers (i.e. not convenient times)
 - b. Systemic barriers (i.e. services not available)
 - c. Particular barriers to non-residential respite
- 5. Are there any ways that respite provision could be improved or modified to better support people?
 - a. Particularly non- residential
- 6. Are there any aspects of respite that are particularly important that should be maintained long term?
- 7. Do you have any recommendation about how you would like respite to be delivered in the future?
 - a. Particularly non-residential respite?