An evaluation of a short break scheme for adolescents with disabilities amongst service users and their parents.

Internationally, families who care for a child or adolescent with disabilities have been found to experience high levels of maternal ill health, stress, depression and family breakdown (Hastings, 2002; McConkey, Gent & Scowcroft, 2011; Stalker, 1996; Veisson, 1999). This is a global issue, affecting individuals, their families and their wider societies (Glidden & Schoolcraft, 2003). In extreme cases, children and adolescents may have to move away from their family to a permanent residential placement (McGill, Tennyson & Cooper, 2006). A potentially more appropriate and cost effective approach is the provision of family support services; predominantly these have taken the form of *short break schemes*, whereby temporary (respite) care is issued to provide short-term relief for the family (e.g. regular afternoon care). This research measured the impact of a short break scheme from the perspective of the service users and their parents by conducting interviews with adolescents with disabilities and quantitative questionnaires with the parents, following a summer short break scheme.

In the UK, there are around 770,000 children and adolescents with disabilities, the majority of whom live at home with their families (Franklin, 2007). In 2007, the UK government recognised the need to extend short break services to help support families who care for their child with disabilities at home (HM Government, 2007). More recently, the UK government has made changes to the Disability Code of Practice (HM Government, 2015), which now highlights the need to engage service users and their families, in the extension of short break services. Despite the on-going emphasis by the UK government to expand short break services for children and adolescent with disabilities, little attention has been paid to adapting these services for the families that are in need (McConkey, Truesdale & Conliffe, 2004). More surprisingly, there is a lack of research assessing current service provisions from the perspective of service users and their families (Staley, 2008).

Problematically, children and adolescents with autism or challenging behaviours may not be able to access short break schemes, as the schemes may not be equipped to manage their particular needs (Chadwick, Beecham, Piroth, Bernard & Taylor, 2002). For example, the Challenging Behaviour Foundation and Tizard Centre (2008) surveyed 314 families across the UK for their experiences of short break services. They found that over a quarter of families reported exclusion and one third reported being turned down from a short break service. Furthermore, 52% of families stated that they needed more short breaks and 40% of families found some short breaks unsuitable. These findings are consistent with MENCAP's Breaking Point survey (2006), which found that 6 out of 10 families did not receive a short break that meet their needs.

The UK government (e.g. Special Educational Needs and Disability Code of Practice, 2015) has identified that local authorities must provide a wider range of short break schemes for children and adolescents with disabilities, particularly as a method to support and enhance the lives of both the services users and their families. Further government recommendations (e.g. Breaks for Carers of Disabled Children Regulations, 2011), have proposed that short break schemes are required to improve the ability for parents to care for their child(ren) with disabilities. Thus, both research conducted with families and government policies highlight the need for short break schemes adapted for children and adolescents with disabilities. Currently there is a lack of research into the adaptations required to meet the requirements of children, and more so adolescents, with disabilities such as autism and challenging behaviours (McConkey, et al., 2011; Mooney, Owen & Statham, 2008). Therefore, one of the main aims of the present study is to evaluate a local short break scheme from the perspective of 1) children and adolescents with a range of disabilities and 2) their parents. Thereby, allowing for

a greater understanding into the adaptions needed for more inclusive short break schemes for both service users and their families.

Impact of short breaks schemes for children and adolescents

Action for Children campaign (2009) commissioned a report that explored the social and economic value created by the effective delivery of local short break schemes. They found a range of positive outcomes for children and adolescents with disabilities, including: improved health through physical activities; improved well-being through social contact and by enjoying activities they had chosen to do; improved ability to form and maintain relationships, increased interaction with peers through participation in mainstream leisure activities; learning and developing a range of skills and abilities through variety of activities; strengthened family relationships through an increased sense of well-being. Furthermore, there is empirical evidence to demonstrate the benefits of short break schemes for children and adolescents with disabilities, such as: fun and enjoyment (McConkey, et al., 2011); high levels of attention (Gerard, 1990); opportunities for new experiences and an increase in social skills (Davies et al., 2005; McConkey et al., 2004); broadening their experiences and giving them opportunities for making new friends and relationships (Prewett, 1999).

In England, Gerard (1990) conducted a cross-sectional survey with family carers of children with severe learning difficulties, who had used one of three local short break services. Carers reported that the quality of life of the child had increased for 81%, 90% and 63% and decreased for 3%, 3% and 11% in each service, respectively. Gerard concluded that overwhelmingly short breaks produce positive effects on the quality of life of children and adolescents. Similar results have been found across Wales and Northern Ireland (McConkey et al., 2004; Swift, Grant & McGrath, 1991), which have noted several benefits, namely: exposure

to new environments; increased opportunity to interact socially with others; involvement in more social activities; increased social skills, growing independence and confidence. It is important to note that some negative findings have been found for service users, for example, a minority of children and adolescents have had unhappy experiences of residential short breaks, including acute homesickness (Oswin, 1984) and general anxiety as a result meeting new people and being in a new environment (Dowling & Dolan, 2001).

Although past research has suggested that most children enjoy short break schemes, the vast majority of data was collected via parents and guardians. It is therefore important that conclusions drawn in the area be interpreted with caution (Chapman, 2013). We argue that more direct research with children and adolescents, across short break services in England, is needed to support the reliability of past findings. Moreover, despite the positive outcomes from previous research, there are two key limitations: firstly, past research has primarily focussed on younger children (aged 12 and under), with less research focusing on adolescents (aged 10 - 17), it is therefore beneficial to explore the provision of short break schemes from a more diverse service user population (e.g., adolescents). Secondly, the majority of past research relies on qualitative evidence from carers (e.g., parents and guardians), thereby hindering an all-inclusive and robust evaluation of short break services designed for their child/children with disabilities.

To overcome the key limitations of previous research, the present study included *interviews from service users* (adolescents with disabilities), providing them with "a voice" in the evaluation of the short break scheme, alongside *quantitative* evidence from parents and/or guardians on the benefits for their child. Thereby, allowing for a more robust measure into the benefits of short break schemes to be calculated. Quantitative data from carers was collected

using the Strengths and Difficulties Questionnaire (SDQ). The SDQ has shown to be a valid

and reliable tool for behavioral screening (Goodman, 1999), research (Goodman & Scott,

1999) and part of clinical assessments (Stone, Otten, Engels, Vermulst, & Janssens, 2010) in

children and adolescent aged 3-16 years old. The use of the SDQ will therefore allow for a

more quantified and reliable calculation into the possible benefits of short break schemes for

adolescents with disabilities.

Impact of short term breaks for families

For parents, carers, guardians and the wider family, several key benefits of short break

schemes have been highlighted, including: having a rest (MacDonald & Callery, 2004);

allowing for a greater engagement in social activities (Chan & Sigafoos, 2001); reduced levels

of stress (Chapman, 2013); increases in relaxation (McConkey et al., 2004); having more time

to spend with partners and other children in the family (Beresford, 1995).

In a review of the literature, Robertson et al. (2010) suggests that short breaks can have

a positive impact on the family as a whole. In addition, having an opportunity to be a "normal"

family was frequently cited by carers as a highly valued outcome of short breaks. Similarly,

Wilkie and Barr (2008) carried out a small-scale qualitative study on parental experiences of

short breaks. Results indicated that the vast majority of parents reported renewed energy levels,

reduced stress and more time available for other activities. Further evidence supporting the

benefits of short break schemes for parents and families comes from correlation studies which

suggest that short breaks are associated with lower parental stress (Chan & Sigafoos, 2001;

Sloper & Turner, 1992).

It should be recognised there are possible negative effects for families associated with

short breaks. There is evidence to suggest that while parents benefit from the use of short

breaks services, this can be accompanied by feelings of guilt (Hartrey & Wells, 2003), loss (Stalker, 1988), and concerns about safety of the child (Duff, 1992). Furthermore, some parents may also experience vicarious anxiety or stress associated with their child's attending short term breaks, for example, when attempting to convince their child to attend (Duff, 1992).

Although prior research has explored the benefits and issues of short break schemes for families (mostly parents), the vast majority of these studies are based on qualitative evidence, producing explanatory evidence (Welch et al., 2010). There is therefore a need for more rigorous evaluation of the benefits of short break services (Pollock, Law, King, & Rosenbaum, 2001). Thus, the current study sought to ensure that the range of parental benefits and outcomes were captured empirically. Accordingly, the Parenting Stress Index (PSI) was used as a method of identifying the parental benefits of short break schemes in a more robust and established manner. The PSI is a clinical and research screening tool designed to identify the systems which are under stress in parents (Abidin, 2012). It is considered to be the most widely used measure of parental stress and is shown to be reliable across a number of studies (Chapman, 2013; Mullins, Aniol & Boyd, 2002), including studies examining parents of children and adolescents with developmental disabilities (Cuskelly, Chant, & Hayes, 2004).

In summary, whilst previous research on short break schemes has identified positive outcomes for both parents and their children, the provision of short term breaks is arguably an area which would benefit from further exploration in order to establish recommendations from both service users and their parents on future areas for development. We argue that this is a vital need in order to develop all-inclusive and person-centred schemes. Accordingly, the overarching aims of this study are two-fold: 1) to evaluate the benefits of a local short break scheme from both a service user and parental perspective and 2) to highlight future

recommendations to help develop all-inclusive and person-centred short break schemes, particularly for adolescents (aged 10 to 17) with complex needs.

Method

Participants

Eleven adolescents accessing a short break scheme over the summer holiday, along with their nine corresponding parents were recruited for the study. Two parent participants had two separate children attending the scheme, accounting for the lower number of parent participants. All participants were recruited from a local charitable organisation in Kent, which provides short break services to children and adolescents with various types of disabilities. The adolescent participant's (10 males and 1 female) ranged from 10 to 16 years of age ($M = 12.7$, $SD = 2.12$), with the majority of service users having a diagnosis of Autism (63%), followed by a Learning Disability (18%) and Cerebral Palsy. The parent participants (2 males and 7 female) age ranged from 32 to 53 ($M = 45.24$, $SD = 6.70$).

Materials

Adolescent interviews. A semi-structured interview schedule was constructed for adolescent participants in order to explore their experiences of and satisfaction with the local short break scheme. Interviews started with broad questions, and then moved onto more specific questions covering the following themes: benefits and drawbacks of scheme, feelings about themselves, skills developed, overall satisfaction and future recommendations. All interviews took place face-to-face on the last day of the summer short break scheme. All interviews were interviewee-led, with some prompts being imposed if necessary. As a result of this method, interviews varied in length from 5 to 20 minutes.

Interviews with service users were conducted, as one of the main aims of the study was to highlight the impact of short break schemes from the perspective of the adolescents, thereby giving a direct voice to the service user. More specifically, previous research has indicated the importance of using this type of method when collecting data from people with disabilities as it serves to reinstate 'people' at the centre of the research agenda, an important element in both disability and in applied research (Hartley & Muhit, 2003). Furthermore, as the UK government has highlighted the need to extend current short break services to better meet the needs of families (HM Government, 2015), it is vital to understand the perspectives of service users if they are to better meet their needs. Interviews can therefore provide insight into the lives of children and adolescents with disabilities and further allow these individuals to give their experiences, in their own words (Schwartz, Staub, Gallucci & Peck, 1995).

Parent questionnaires. Data collection from parents consisted of short self-report questionnaire derived from two adapted standardised measures:

Strengths and Difficulties were measured using and adaptation of the Strengths and Difficulties Questionnaire – Parent Report version for parents of 4-17 year olds (SDQ**,** Goodman, 1999). The primary caregiver of the adolescent short break user was asked to rate all original 25 items of the scale (e.g. "Often has temper tantrums or hot tempers"). The response scale was adapted to a 5-point scale ("a lot less", "slightly less", "the same", "slightly more" and "a lot more") to indicate degree to which the item has, or has not, changed since the start of the scheme. The questionnaire comprises of the following sub-scales: emotional problems, conduct problems, hyperactivity, peer relationship problems and prosocial behaviours. Firstly, all five of the reverse items were reversed coded and then all 25 items were dummy coded (-2 = "a lot less", -1 = "slightly less", 0 = "the same", 1 = "slightly more" and 2 = "a lot more"). A

composite mean score was then calculated, good internal reliability was found for this measure (Cronbach's alpha, .77).

Parental Stress Index was measured using an adaptation of the Parenting Stress Index (PSI, Abdin, 1995) whereby responses to 32 items were captured on a 5-point scale ("a lot less", "slightly less", "the same", "slightly more" and "a lot more") to indicate the degree to which the item has or has not changed since the start of the scheme. All 32 items were dummy coded (-2 "a lot less", -1 "slightly less", 0 "the same", 1 "slightly more" and 2 "a lot more") and then a composite mean score was them calculated. Excellent internal reliability was found for this measure (Cronbach's alpha, .96).

Procedure

As previously mentioned, all participants were recruited from a local short break scheme which offers services for all children and adolescents with a range of disabilities. The scheme was carried out three days a week (Monday, Wednesday and Friday) for a month over the summer holidays (14 July – 8 August 2014) and was opened to adolescents aged 10 to 18 who had a disability. The scheme incorporated a combination of unstructured youth activities (e.g., pool tables, computers, game consoles and outside play), along with various staff-led sessions (e.g., cooking classes, computing sessions, group games) to help in developing a number of social and life skills. Each session cost £10, with parents who had more than one child attending receiving a discount depending on circumstances.

Although, generally twenty adolescents access the club on a day to day basis, eleven adolescents and nine corresponding parents attending the local short break scheme agreed to take part in the study. Consent for both the adolescents and parents participation was sought through written consent from each parent. All parents were approached during the first week of

the summer scheme and were provided with an information sheet informing them about the research. Parents who were willing for both their child and themselves to take part in the research were asked to provide written consent for both parties. Data collection commenced on the last two days of the summer scheme. Parent participants were asked to complete the *Strengths and Difficulties Scale* and the *Parental Stress Index*, they were also asked a number of short answer questions in regards to their satisfaction of the short break scheme and future recommendations. All questionnaires took approximately 20 minutes to complete. Those parents who had more than one child attending the scheme were asked to complete one questionnaire pack for both children. Verbal assent was obtained from the adolescent participants before taking part in the semi-structured interviews. Adolescent participants were introduced to the researchers at the start of the scheme, informed of the research and the opportunity to take part in the interview at the end of the scheme; this procedure was followed in order to put adolescent participants at ease, particularly those with Autism. The purpose of the semi-structured interviews were to explore the adolescent's overall perception of the short break scheme. Whilst the interviews were semi-structured, they were also participant-led and therefore interview times ranged from 5 to 45 minutes. Upon completion of data collection, all participants were thanked for their time and fully debriefed.

Data Analysis

Thematic analysis was used to identify themes within the interviews and short answers from the parental self-report questionnaires. Two researchers independently analyzed all 11 adolescent interviews and short answers from parent questionnaires using Luborsky's (1994) technique, which is suitable for analyzing qualitative data obtained from semi-structured interviews and open-ended questions. The themes from participants were generated from

reoccurring comments in relation to their experiences, perceptions and overall satisfaction with the scheme. Themes were identified using an inductive ('bottom up') method (Frith & Gleeson, 2004), this type of approach involves identifying patterns which are strongly linked to the data (Patton, 1990), rather than specific questions asked to the participants. If both researchers were in agreement about an identified theme and there was a 70% agreement of the number of participants falling in the theme, the theme was viewed as valid. Any discrepancies were discussed and where appropriate resolved or accommodated through further refinement of the coding framework. This approach was applied as there was no specific research question or theoretical underpinning, which in turn, generated the exploration of specific themes. The quantitative data generated from parent participants ($N = 9$) was analyzed using one sample t-tests to test for significant differences since the start of the scheme (i.e. tested for significant differences from 0=indicating no change). This mixed method design was used to triangulate the qualitative and quantitative data (Lobe, 2008).

Results

Table 1 provides a summary of the patterns found within the thematic analysis, all identified patterns were placed within two overarching themes: (1) Benefits and (2) Overall Satisfaction. Each theme and corresponding sub-themes are presented below with supporting verbatim patterns from service user interviews, along with supporting statistical analysis from parent participants.

Insert Table 1 here

Benefits

When examining the benefits, this theme refers to the positive impact on the service user's quality of life. All adolescent and parent participants revealed a number of vital benefits

for the short break scheme users. These benefits were further broken down into two sub-

themes; (1) Psychological well-being and (2) Social interaction.

Psychological well-being. When adolescent participants were asked if there were any

benefits or learning outcomes to attending the scheme, all participants made reference to the

benefits in their psychological well-being, with the vast majority ($N = 9$, 81%) noting the

impact on their emotional development. This pattern included a greater sense of belonging and

enjoyment by the adolescents, along with a decrease in emotional symptoms such as anger,

anxiety, fear and unstable emotions. For example, when adolescent participants were asked

about whether they felt a sense of belonging at the scheme, all participants noted this feeling as

a positive reinforcement to their short break enjoyment. For instance, as one participant

expressed, *'…I've been coming here for years… I know all the staff and the other kids… I fit,*

all the kids are like me (P5). Similarly, another participant talked about the enjoyment they got

from the summer scheme, *'…There is always something to do, you know? And like, every day,*

you don't know, it's different and fun'. (P9). We note that this theme does not capture

physiological measures of health and wellbeing, but rather a psychological conception of

wellbeing, including social wellbeing (Ruff, 1989).

This was also partially supported by the quantitative responses from parent participants.

A one-sample t-test was used to examine parental reports of their child's emotional problems

upon completion of the scheme. Results indicated a marginally significant reduction in

adolescent's emotional problems sub-scale of the Strengths and Difficulties Questionnaire, $t(9)$

$= -2.42$, $p = .052$, including factors such as unhappiness, worry, nervousness and fear. These

benefits were further echoed by all parent participants when they were given the opportunity to

elaborate on examples, whereby they noted that the life skills of their child vastly improved

over the course of the summer. These skills included; greater communication, appropriate interaction, effective listening and building new relationships.

　　　　Social interaction. Another sub-pattern which developed within the benefit theme emerged when adolescent participants were asked what they liked best about the short break scheme. All participants made reference to some form of social interaction, with the majority ($N = 9$, 81%) responding that the various group activities, such as the days out, organised games, local trips and use of technology, were their favourite aspects of the scheme. For example, as one adolescents stated; *…well, instead of sitting at home on my Xbox, which I normally do, it's good to get out a bit and see more friends. So, it's better that I am being more social …' (P1).* Similarly, another participant explained how he enjoyed the group activities, *'…like going to beach, going to, like, even castle, castles, and er going out to the seaside' (P10).* Most of the adolescent participants ($N = 8$, 72%) also stated that the new friendships they made with staff and other adolescents was their favourite aspects of the scheme. For instance, one participant exampled how their favourite activity was hanging out with *'friends, like in the computer room, chatting to the others saying what are they doing (P3).* Another participant explained how this was the only opportunity he had to see his friends, *'now that I've left the school I was at, it's the only place I can see some of my friends from there' (P10).*

　　　　Further support for the benefits of adolescent's social interaction came from quantitative responses from parent participants. A one-sample t-test was used to examine the conduct problems (i.e., aggressiveness, temper issues and anger regulation) and hyperactivity problems (i.e., restlessness, distraction and fidgetiness) sub-scales from the Strengths and Difficulties Questionnaire. The results indicated a significant reduction in their negative conduct, $t(9) = -2.70$, $p = .036$, and hyperactivity $t(9) = -2.83$, $p = .030$. When prompted to

elaborate on their responses, all parents further noted that one of the main skills their child developed during the scheme was social skills, in particular, building and maintaining new friendships.

Overall satisfaction

      This theme refers to the fulfilment of participant's expectations and needs, along with the pleasure they derived from the short break scheme. Whilst all adolescent and parent participants noted great overall satisfaction with the short break scheme, key recommendations were also noted. The patterns which emerged within this theme were therefore reflective of participants (1) Positive experience and (2) Future recommendations.

      Positive experience. When adolescent participants were asked about their overall experience at the scheme, *all* found the scheme to be a positive experience. In particular, there was a noteworthy emergence of discussion around the great satisfaction of new experiences, with all participants reporting at least one of the following: learning new things, new activities or new friendships as pivotal in their positive experiences. For example, as one participant explained, *'I like coming to the youth centre, I like going out seeing my friends and some of the activities they do here and some of the trips we go on are quite enjoyable' (P1).* Another young person responded that they were satisfied with *'everything really. Obviously I like coming here, having a laugh. Err, and having fun' (P2).*

      Furthermore, all parent participants also expressed that the scheme was a very positive experience for both themselves and their child, further stating that they would recommend the scheme to others in similar situations. With that, all parent participants also expressed greater satisfaction with their child's behaviour and their relationship with their child upon completion of the scheme. These responses were further supported by a reported decrease in Parental

Stress, $t(9) = -4.34$, $p = .005$, including factors such as; stresses associated with restrictions on

life, conflict with child's other parent and social support. As well as a significant reduction in

parental-child dysfunctional interaction, $t(9)= -4.58$; $p=.004$, including factors such as;

believing their child is not meeting their expectations and stress problems related to the child's

behaviour.

In summary, the key themes that emerged from the adolescent's experience of the short

break scheme were the benefits and overall satisfaction. This was further supported by the

parent's reports of reductions in their child's emotional, conduct and hyperactivity problems

and reductions in their own levels of parental stress. From the parental reports, the peer

problems and prosocial sub-scales of the Strengths and Difficulties Questionnaire did not

significantly change, $t(9) = -1.59$, $p = .162$ and , $t(9) = 1.58$, $p = .166$, respectively. Moreover,

these areas did not emerge as themes from the adolescent interviews, therefore, this could be an

area for future development in short break schemes. Additional future recommendations will

now be delineated.

Future recommendations. The final sub-pattern which developed within the overall

satisfaction theme emerged when both adolescent and parent participants were asked if they

had any future recommendations. The vast majority ($N = 10$, 91%) of adolescents and all

parent participants felt the need for a young adult scheme (18 years +) developing from the

youth short break scheme. For example, one adolescent participant expressed; *'... I think for*

the older people, for the people like that. I think once they are eighteen or over they should

have a… ERM, a 'age and beyond' one…' (P2). The adolescent participants further

emphasized the real need for a young adult scheme, as one individual explained, *'...there are*

some older people here but after about the age of… twenty-one… [the scheme] sort of goes off, there is absolutely nothing they can offer' (P10).

Further recommendations from adolescent participants all related to the need for more funding to access better resources, implement more activities and provide a longer scheme. For example, one participant indirectly described the need for more staff, *'they used to have volunteers come over and it sort of mixed people who were disabled with people who were normal and it was quite nice, but there's not been any of that this year' (P10).* Whilst another described the need for a more modern and accessible building, *'what I would like them to do is just like demolish the whole building and then, like, re-build it up, so it's more improved and more stylish. Because you can see like… it's not all been done properly' (P3).* Some participants also described how they would like the scheme to be longer so they could have *'more time so we can play more' (P7).* Other participants wanted *'more trips like water sports or maybe, or, just, more hands-on trips' (P1)*; these thoughts were further echoed by the parents, for instance, parents indicated that introducing a programme in which young people learnt skills needed for independent living would be beneficial.

Discussion

This study has provided overarching support for the use of short break schemes, as they contribute to the maintenance and development of positive psychological well-being of both adolescents and their parents. Indeed, *all* participants stated that they were extremely satisfied with the short break schemes provided. One of the key discoveries is that reports of adolescent's psychological well-being was significantly improved by respite, these findings were strengthened by both qualitative data from the adolescent's and supporting quantitative data from parents, providing more inclusive support from both the service users and parents

perspective. The study's findings also strongly echoed the conclusions from the Action for Children campaign (2009), advocating that short breaks for adolescent can have numerous benefits. More specifically, improvements to well-being were illustrated through the following: social contact, enjoying activities in which the children had chosen to engage and improved ability to form and maintain healthy relationships. In addition, the findings from the research are some of the first to actively put into practice the UK government's emphasis on the need to focus on the participation of service users and their guardians in the evaluation and extension of short break services (HM Government, 2015). In particular, to date, there has been little attention paid to incorporating the opinions of families that use these services (McConkey, et al., 2004; Staley, 2008). These key points will now be discussed in more detail.

This investigation found new evidence to further support previous research that highlights the various benefits of short break schemes for children and adolescents with disabilities. More specifically, the current study found that short breaks were able to reduce adolescent's emotional difficulties, which can generally range from feelings of anger and anxiety to fear. The results further indicated that there was a significant reduction in adolescent's emotional stress and instability, including factors such as unhappiness, worry, nervousness and fear. These key findings also provide support for the benefits of short break schemes for families, in particular, previous research has indicated that adolescents with disabilities place greater emotional and physical pressure on their families (Hastings, 2002; McConkey, et al., 2011). Thus, it could be suggested from the present study that short break schemes can help reduce this pressure by providing a much-needed rest. Along with reductions in emotional difficulties, findings further indicated a significant reduction in adolescent's

negative conduct and hyperactivity. This is a promising outcome that requires further exploration in future research.

In terms of social interaction, the current study highlighted social interaction with others as one of their favourite aspects of the scheme. These findings support previous research which acknowledges that respite can potentially reduce social isolation, along with providing opportunities for children and young people to experience social interaction with their peers through different types of activities (McConkey, et al., 2004; Chan & Sigafoss, 2001). Findings further demonstrated that the progression of social skills was most evident across the adolescents. This was a significant finding because prior research suggests that children and young people with disabilities tend to find it more challenging to socialise with peers (Buckley, Bird & Sacks, 2002; Child Development Institute, 2015). Therefore, not only does this inquiry add to current knowledge, it has highlighted it as an area that may benefit from greater exploration. Similarly, new friendships were illustrated as being a significant feature of short breaks and several of the participants emphasised this as one of the best aspects of short breaks. This supports previous research findings that children and young people want to befriend and engage with others (HM Government, 2007). Therefore, this investigation adds to the wealth of knowledge that social skills and new friendships can develop from short breaks.

In regards to the adolescents and parents overall satisfaction with the short break scheme, it was discovered that the parents and their children were content with the scheme, with some of the essential features being identified as: making friends, new experiences and having fun. This is extremely valuable as in the current literature it was demonstrated that not all short break schemes met the service user's needs (Challenging Behaviour Foundation and

the Tizard Centre, 2008; MENCAP, 2006). Similarly, it has been identified that opportunities for new experiences were required but not always delivered (Davies et al., 2005; McConkey et al., 2004). Interestingly, Robertson and colleagues (2011) proposed that what children and their families wanted from short break services was the following: fun; to be provided with a range of experiences; a choice of services to suit the child's needs; confidence that the service will care for the child well; services that were reliable and flexible; local services where good relationships can be built and finally good information and support.

All parent participants further expressed greater satisfaction with their child's behaviour and their relationship with their child upon completion of the scheme. These responses were supported by a decrease in parental distress, including factors such as; stresses associated with restrictions on life, conflict with child's other parent, social support and depression. As well as a significant reduction in negative parent-child interactions, for example, believing their child is not meeting their expectations and stress problems related to the child's behaviour. This is extremely encouraging, as the limited literature has found that short breaks may play a role in improving family relationships (Stalker 1988, Stalker & Robinson 1994).

When adolescents and parents were asked about any future recommendations, all participants identified more resources were strongly shown to be required for short breaks, such as games, activities and longer breaks. These results are supported by prior evidence showing that a greater frequency, number and longer duration of short breaks are requested by parents and their children (Action for Children, 2009; Challenging Behaviour Foundation & Tizard Centre, 2008). A unique contributing factor of this study is the identification as to why longer breaks were required by adolescents, as they wanted to spend more time engaging with their peers and activities provided. Specifically, some of the adolescents commented *they*

wanted *'more time to play'* or '*speak to their friends'*. However, with more resources, more financial funding is required (Holmes, McDermid, & Sempik, 2010). That being said, with the UK governments report on Special Educational Needs and Disability Code of Practice (2015), there is further pressure for the public bodies in providing opportunities for new approaches to help make a difference in the lives children and young people with disabilities. Accordingly, extending the current results further to evaluate specific resources and benefits of these resources would be extremely valuable.

Another key recommendation that the majority of both adolescent and parents expressed was the need for an adult scheme for young adults over 18 years of age, to help with the transition into adulthood. This study highlighted the need for a scheme that provides young people the opportunity to develop skills needed for independent, such as: cooking, managing finances, travelling and completing tasks independently. These findings highlight an area for future exploration and consideration; as continuing short break services into adulthood requires more funding to be in place, yet due to the recent austerity measures there has been significant cut backs in funding (Local Government Association, 2014). In relation to children and adolescent funding, the local councils have been cutting children and adolescent's services funding considerably over the last five years (County Council Network, 2015). These recent cutbacks go against the findings of the current study and also the government's recent provisions to the Disability Code of Practice (2015), which places a high degree of focus on supporting young people up to the age of 25 years old. It is therefore crucial that future research explores the provision of short break services into adulthood.

Overall, the intention of this study was to integrate the personal experiences adolescents using a short break scheme in conjunction with their parents' experiences, as a process of

moving forward to create more all-inclusive short break schemes. More specifically, the study has produced new and triangular evidence to support the argument that short-term breaks are beneficial for both adolescents and their parents' emotional health and well-being. Of particular significance was the method by which these results were obtained. Previous research within the area has primarily relied on data from family member's perception. Whereas, the current study applied a person-centered approach, consulting the adolescents directly about their views in regards to the benefits of short break schemes. These methods are fundamental as they incorporated the views of the individuals who most benefit from short break schemes. The methods further echoed the recent changes to the Disability Code of Practice, which focuses on the participation of children in the changes to short break schemes (HM Government, 2015).

That being said, there are a number of limitations of the study that need to be addressed in future research. For instance, the current study gathered post data from parental participants and asked them to compare their child's changes from the start of the programme. As such, future research could utilize a longitudinal design, although we appreciate the difficulty in collecting pre-post or multiple data points in this applied context. We also acknowledge that future evaluations should collect data on attrition and follow up those who decide to leave a summer break scheme. In conclusion, the current study highlights the need for a transition short break scheme to support adolescents with disabilities into adulthood. This is the first step towards the exploration of what additional support short break services could provide, along with the important benefits of such services from the perspective of both service users and their families. Future research could build upon the foundations created within this study and help to ensure that short break services are meeting the needs of those involved in these services.

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