

Canterbury Christ Church University's repository of research outputs

http://create.canterbury.ac.uk

Please cite this publication as follows:

Spruin, E., Abbott, N. and Holt, N. (2017) Examining the experiences of a short break scheme amongst adolescents with disabilities (service users) and their parents. International Journal of Disability, Development and Education, 64. pp. 1-15. ISSN 1034-912X.

Link to official URL (if available):

http://dx.doi.org/10.1080/1034912X.2017.1348599

This version is made available in accordance with publishers' policies. All material made available by CReaTE is protected by intellectual property law, including copyright law. Any use made of the contents should comply with the relevant law.

Contact: create.library@canterbury.ac.uk



Impact of short break schemes
An evaluation of a local short break scheme for adolescents with disabilities: Measuring the impact on disabled adolescent users and their parents.

Children and adolescents with learning disabilities and/or severely challenging behaviour can place particular strains on their families. This often leads to maternal ill health, depression and family breakdown, which can be very stressful and threaten family wellbeing (Hastings, 2002; McConkey, Gent & Scowcroft, 2011). In extreme cases, children may have to move to high cost residential placements (McGill et al., 2006). A potentially more appropriate and cost effective approach is the provision of family support services; predominantly these have taken the form of 'respite' short break provision and in 2007 the UK government recognised the need to extend such services (HM Government, 2007). Most recently, the UK government has made changes to the disability code of practice, further highlighting the need to focus on the participation of children and parents in the extension of these services (HM Government, 2015). Despite the on-going emphasis by the UK government to expand short break services for children with complex needs, little attention has been paid to adapting these services for children and families that have complex needs (Emerson, 2001; McConkey, Truesdale & Conliffe, 2004; Staley, 2008). More surprisingly, there is a lack of research assessing current service provisions from the perspective of service users and their families (Audit Commission, 2003).

Problematically, children and adolescents with additional needs due to autism or challenging behaviours may not be able to access short break schemes, as they are not equipped to manage their needs (Chadwick et al., 2002). For example, in 2008 the Challenging Behaviour Foundation asked 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 need more short breaks and 40% of families found at least some of their short breaks

unsuitable. These findings are consistent with MENCAP's "Breaking Point" survey (2006), which found that 6 out of 10 families do not receive a short break that meets their needs.

In addition, the Governments report on Special Educational Needs and Disability Code of Practice (2015:72) identified that 'local authorises must provide a range of short breaks for disabled children', particularly as a method to support and enhance the children and families lives. Further government recommendations such as 'the Breaks for Carers of Disabled Children Regulations (2011) proposed that short breaks are required to improve the ability for parents to care for their disabled child/children. Thus, both research conducted with families and government policy highlight the need for short break schemes adapted for disabled children and adolescents. Moreover, there is a lack of research into the adaptations required to meet the requirements of children, and more so adolescents, with complex needs, such as autism and challenging behaviours (McConkey, Gent & Scowcroft, 2011; Mooney, Owen & Statham, 2008). Therefore, one of the main aims of the present study is to evaluate the impact of a local short break scheme on disabled adolescents with additional needs, and their parents. Thereby allowing for a greater understanding into the adaptions needed for a more inclusive short break schemes for adolescents.

Impact of Short Term Breaks for Adolescents

Action for Children and the Every Disabled Child Matters Campaign (2009) commissioned a report which explored the social and economic value created by effective local delivery of short break schemes. They found a range of positive outcomes for disabled children, 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 for the disabled child, including: fun and enjoyment (McConkey, Gent & Scowcroft, 2011; Mencap, 2010), high levels of attention (Gerard, 1990), opportunities for new experiences (Davies et al., 2005; McConkey et al., 2004) and an increase in social skills (Short-DeGraff & Kologinsky, 1987; Starkey & Sarli, 1989; Tarleton & Macaulay, 2002; McConkey et al., 2004). In addition, Prewett (1999) conducted a study which identified that disabled children themselves benefit from having short breaks in terms of broadening their experiences and giving them opportunities for making new friends and relationships.

Gerard (1990) conducted a cross-sectional survey of family carers (N=253) in England of children with severe learning difficulties, who had used one of three local authorises short break services. The study found that quality of life improved for 81%, 90% and 63% and been affected detrimentally for 3%, 3% and 11% in each service, respectively. Gerard concluded that short breaks produce overwhelmingly positive effects on the quality of life of children, according to reports by carers. Similar results have been found across Wales and Northern Ireland. For example, a Welsh study which explored the benefits of short breaks with 150 family carers of children with developmental disabilities (Swift, Grant & McGrath, 1991). Several benefits were listed including; exposure to new environments; increased social skills, growing independence and confidence. Similarly, a study in Northern Ireland asked 108 parents about the perceived benefits of short breaks for their child with developmental disabilities. Results found that parents believed their children had the opportunity to interact

socially with others, be exposed to a different environment and getting involved in more social activities (McConkey et al., 2004).

Although research has suggested that most children enjoy short break schemes, the majority of data collected was via parents and carers. It is therefore important that conclusions drawn in the area be interpreted with caution (Chapman, 2013). It could therefore be argued that more direct research is needed across short break services in England to support the reliability of these findings. Moreover, despite the positive outcomes from previous research, there are two key limitations: 1) the majority of past research relies on qualitative evidence from carers; thereby hindering an all-inclusive and robust evaluation of short break services designed for their children with disabilities and 2) past research has focussed on children, rather than adolescents; the provision of short break schemes for adolescents reveal different benefits and issues.

To overcome the key limitations of previous research, the present study included interviews with the adolescents themselves, to provide them with "a voice" in the evaluation of the short break scheme, along with quantitative evidence from carers on the benefits for their adolescent child. Thereby allowing for a more robust measure into the benefits of short break schemes be calculated. Quantitative evidence 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 (e.g., Glazebrook et al., 2002; Goodman, 2004; Goodman, Renfrew & Mullick, 2000), research (e.g., Goodman, 1999; Goodman & Scott, 1999) and part of clinical assessments (e.g., Stone, Otten, Engels, Vermulst, & Janssens, 2010; Zwirs et al., 2008) in children and young people aged 3 -16 years old. The validity and reliability of the SDQ extends to both community (e.g., Edmunds et al., 2005; Kashala et al., 2005; Koskelainen et al., 2001)

and clinical samples (e.g., Becker et al. 2004; Goodman, 2001). The use of the SDQ will therefore allow for a more quantified and reliable calculation into the possible benefits of short break schemes on young people with disabilities.

Impact of Short Term Breaks for parents and the family

For parents and families, 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 parents and 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 likely to decrease parental stress (e.g., Chan and Sigafoos, 2001; Sloper & Turner, 1992).

It should be recognised there are possible negative effects associated with short breaks. There is evidence to suggest that while parents and carers benefit from the use of short breaks services, this can be accompanied by feelings of guilt (Hartrey & Wells, 2003), loss (Stalker, 1998), and concerns about safety of the child (Duff, 1992). A minority of children 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). Furthermore, some parents may also experience vicarious anxiety associated with their children's short term breaks (Duff, 1992).

Although prior research has explored the benefits and issues of short break schemes for parents and families, the vast majority of these studies are based on qualitative evidence, producing explanatory evidence (Welch et al., 2010). There is therefore a clear need for more rigours evaluations of the benefits of short break services (Pollock, Law, King, & Rosenbaum, 2001). The current study therefore sought to ensure that the range of parental benefits and outcomes were captured more 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 (Bigras et al., 1995; Chapman, 2013; Mullins et al., 2002), including studies examining parents of children with developmental disabilities (e.g., Cuskelly, Chant, & Hayes, 1998).

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 parents and adolescents on future areas for development. We argue that this is a vital need to in order to develop all-inclusive and person-centred schemes, particularly in this age group. Accordingly, the overarching aims of this study are two-fold: 1) to evaluate the impact of a local short break scheme from both an adolescent service users and parental perspective

and 2) to highlight future recommendations to help develop all-inclusive and person-centred schemes for adolescents.

Method

Participants

Eleven disabled 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 adolescents attending the scheme, accounting for the lower number of parent participants. All participants were recruited from a local organisation which provides short break services to children and adolescents with various types of disabilities. Once written parental consent was obtained, verbal assent was obtained from their child. The adolescent participant's (10 males and 1 female) ranged from 9 to 16 years of age (M = 12.7, SD = 2.12), with the majority of adolescents 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 (see Appendix 1 for interview protocol). 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.

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, 2001). 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 (0 "a lot less", 2 "slightly less", 3 "the same", 4 "slightly more" and 5 "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 them 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 (0 "a lot less", 2 "slightly less", 3 "the same", 4 "slightly more" and 5 "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, especially for children with 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 young people with disabilities and special needs aged 11 to 18. 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 children access the club on a day to day bases, 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. Parents 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 obtain form the adolescent participants

before taking part in the semi-structured interviews. The purpose of this semi-structured interview was 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 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. 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 Experience. Each theme and corresponding sub-themes are presented below with supporting verbatim patterns from adolescent 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 adolescent'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) Well-being and (2) Social interaction.

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 overall 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).

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 young person 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 child 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 young people'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* young people 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 were not significantly reduced, 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 young people and all parent participants felt the need for a young adult scheme (18 years +) developing from the youth short break scheme. For example, one individual 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 young people 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 child 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 the holistic health and 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 the adolescent's overall 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 and Every Disabled Child Matters Campaign's (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 provisions to expand short break services for children with complex needs (HM Government, 2007) and enabling children and parents of these services to have a voice in the changes being made to these provisions (HM Government, 2015). 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 disabled children. 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 complex needs place greater emotional and physical pressure on their families (Hastings, 2002; McConkey, Gent & Scowcroft, 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 to experience social interaction with their peers through different types of activities (McConkey, Truesdale & Confliffe, 2004; Tarleton & Macaulay, 2002; 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 adolescents with special needs 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 want to befriend and engage with others (Aiming High for Disabled Children, 2007; Prewett, 1999).

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 families 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; Prewett, 1999). Interestingly, Robertsons et al. (2011) propose that what children and their families wanted from short break services was fun and 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 parental-child dysfunctional interaction, 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 that has been carried out 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 pilot and evaluate specific resources and benefits of these resources would be extremely valuable.

Another key recommendation that the majority of both children 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 families' 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 wellbeing. 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 UK Governments White Paper (2001) Valuing people: a new strategy for learning disability in the 21st century, which emphasized the need to work in partnership with service users to ensure services are meeting their direct needs, along with 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 which 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. In conclusion, the current study highlights the need for a transition short break scheme to support adolescents with special needs into adulthood. This is the first step towards the exploration of what more short break services should do, 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.

References

- Action For Children (2009). The Social and Economic Value of Short Breaks. [Online]

 Available at:
 - https://www.actionforchildren.org.uk/media/52623/the_social_and_economic_value_of _short_breaks_full.pdf. Accessed: 8th March 2015.
- Abidin, R. R. (2012). Parenting stress index (4th ed.). Lutz, FL: PAR.
- Aiming High for Disabled Children developing skills (2007). *Better Support For Families*.

 [Online] Available at:
 - http://webarchive.nationalarchives.gov.uk/20130401151715/http://www.education.gov.uk/publications/eOrderingDOwnload/PU213.pdf. Accessed: 8th March 2015.
- Audit Commission (2003). Services for disabled children: A review of disabled children and their families. Retrieved from: http://archive.audit-commission.gov.uk/auditcommission/sitecollectiondocuments/AuditCommissionReports/NationalStudies/Disabled-report.pdf
- Beresford, B. (1995). Expert Opinions: A National Survey of Parents Caring for a Severely Disabled Child. Bristol: Policy Press.
- Becker, A., Woerner, W., Hasselhorn, M., Banasschewski, T., & Rothenberger, A. (2004).

 Validation of the parent and teacher SDQ in a clinical sample. *European Child and Adolescent Psychiatry 13*, 11-16.
- Bigras, M., LaFreniere, P., & Dumas, E. (1995). Discriminate Validity of the Parent and Child Scales of the Parenting Stress Index. *Early Education & Development*, 72,160-170.
- Bose, R. (1991). The effect of a family support model on maternal mental health of mothers caring for children with mental handicaps. *Research Policy and Planning 9*, 2–8.
- Buckley, S., Bird, G., & Sacks, B. (2002). 'Social development for individuals with Down

- syndrome-An overview.' Down Syndrome Issues and Information.
- Chadwick, O., Beecham, J., Piroth, N., Bernard, S., & Taylor, E. (2002). Respite care for children with severe intellectual disability and their families: Who needs it? Who receives it?. *Child and Adolescent Mental Health*, 7(2), 66-72.
- Challenging Behaviour Foundation & Tizard Centre (2009). The Challenge: Getting a break.

 Chatham, Kent: Tizard Centre University of Kent/Challenging Behaviour Foundation.

 [Online] Available at: http://www.challengingbehaviour.org.uk/learning-disability-files/Short-breaks-report.pdf. Accessed: 8th March 2015.
- Chan, J. & Sigafoos, J. (2001). Does respite care reduce parent stress in families with developmentally disabled children? *Children and Youth Care Forum 30*, 253-263
- Chapman, M. (2013). An investigation into the parental stress levels of families who have children with severe developmental disabilities using residential short breaks: a contributing factor of its stress reduction impact. (Unpublished Doctoral thesis, City University London).
- Child Development Institute (2015). Helping Your Child with Socialization

 [Online] Available at:

 http://childdevelopmentinfo.com/ages-stages/school-age-children-development-parenting-tips/socialization/ Accessed: 27th March 2015.
- Cohen, S. & Warren, R. (1987). Preliminary survey of family abuse of children served by

 United Cerebral Palsy Centers. *Developmental Medicine & Child Neurology*, 29(1), 12-18.
- Cope, C. (2003). Fulfilling lives: inspection of social care services for people with learning disabilities. Social Services Inspectorate, Department of Health.
- County Council Network (2015). Local Government Finance Settlement 2015-16 Consultation.

- [Online] Available at: www.countycouncilsnetwork.org.uk/library/july-2013/file9. Accessed: 27th March 2015.
- Cramer, H. & Carlin, J. (2008). Family-based short breaks (respite) for disabled children:

 Results from the fourth national survey. *British Journal of social work*, *38*(6), 1060-1075.
- Cuskelly, M., Chant, D., & Hayes, A. (2004). *Parental stress in fathers and mothers of children with Down syndrome: Are the processes the same?* Paper presented at the 12thWorld Congress of the International Association for the Scientific Study of Intellectual Disability (IASSID). Montpellier, France.
- Davies B., Collins J., Steele R., Cook K., Brenner A. & Smith S. (2005). Children's perspectives of a pediatric hospice program. *Journal of Palliative Care*, 21, 252-261.
- Dowling, M. & Dolan, L. (2001). Families with children with disabilities-inequalities and the social model. *Disability & Society*, *16*(1), 21-35.
- Duff, G. (1992). Respite Choice. Nursing Times, 88(33), 65-66.
- Edmunds, S., Garratt, A., Haines, L., & Blair, M. (2005). Child Health Assessment at School Entry (CHASE) project: Evaluation in 10 London primary schools. *Child: Care, Health and Development, 31,* 143–154.
- Emerson, E. (2001). *Challenging Behaviour: Analysis & Intervention in People with Severe Intellectual Disabilities.* 2nd Edn. Cambridge: Cambridge University Press.
- Gerard, K. (1990). Determining the contribution of residential respite care to the quality of life of children with severe learning difficulties. *Child: Care, Health and Development, 16,* 177-188.
- Glazebrook, C., Hollis, C., Heussler, H., Goodman, R., & Coates, L. (2002). Detecting emotional and behavioural problems in paediatric clinics. *Child: Care, Health and Development*, 29, 141–149.

- Goodman, R. (1999). The extended version of the Strengths and Difficulties Questionnaire as a guide to child psychiatric caseness and consequent burden. *Journal of Child Psychology and Psychiatry*, 40, 791–799.
- Goodman, R., Renfrew, D., Mullick, M. (2000). Predicting type of psychiatric disorder from Strengths and Difficulties Questionnaire (SDQ) scores in child mental health clinics in London and Dhaka. *European Child and Adolescent Psychiatry*, *9*, 129-134.
- Goodman, R., & Scott, S. (1999). Comparing the Strengths and Difficulties Questionnaire and the Child Behavior Checklist: Is small beautiful? *Journal of Abnormal Child Psychology*, 27, 17–24.
 - Government HM (2007). *Aiming High for Disabled Children: Better Support for Families*. HM Treasury & Department of Education & Skills. London: HMSO.
 - Government HM (2011). Breaks for Carers of Disabled Children Regulations. Department of Health. London: HMSO.
 - Government HM (2015). *Special Educational Needs and Disability Code of Practice*. Department of Health. London: HMSO.
 - Government HM (2001). White Paper: Valuing people: a new strategy for learning disability in the 21st century. Department of Health. London: HMSO.
 - Hartrey, L. & Wells J. (2003). 'The Meaning of Respite Care to Mothers of Children with Learning Disabilities: Two Irish Case Studies.' *Journal of Psychiatric & Mental Health Nursing*, 10, 335-342.
 - Hastings, R. (2002). 'Parental stress & behaviour problems of children with developmental disability.' *Journal of Intellectual & Developmental Disability*, 27(3), 149–160.
 - Heslop, P. & Robinson, C. (2004). *Befriending: More than Just Finding Friends?* Bristol: Shared Care Network.
 - Holmes, L., McDermid, S. & Sempik, J. (2010). The costs of short break provision.

 MacDonald, H. & Callery, P. (2004). Different meanings of respite: a study of

- parents, nurses and social workers caring for children with complex needs. *Child: Care, Health and Development, 30,* 279-288.
- Kashala, E., Elgen, I., Sommerfelt, K., Tylleskar, T. (2005). Teacher ratings of mental health among school children in Kinshasa, Democratic Republic of Congo. *European Child and Adolescent Psychiatry 14*, 208-215.
- Koskelainen, M., Sourander, A., & Kaljonen, A. (2001). The Strengths and Difficulties

 Questionnaire among Finnish schoolaged children and adolescents. *European Child*and Adolescent Psychiatry, 9, 277–284.
 - Local Government Association (2014). *Adult Social Care Funding: State of the Nation Report*. [Online] Available at:

 http://www.local.gov.uk/documents/10180/5854661/Adult+social+care+funding+2
 014+state+of+the+nation+report/e32866fa-d512-4e77-9961-8861d2d93238
 Accessed: 27th March 2015.
 - Matthiessen, B., Avdagovska, M., Mardhani-Bayne, L. & Price, A. (2009). Respite Care Demonstration Project. Final Report: Summary of The Findings, Alberta Disabilities Forum. [Online] Available at: http://www.hse.ie/eng/services/publications/Disability/Homesharingrreport%20201 2.pdf/ Accessed: 28th February 2015.
 - McConkey, R. & Truesdale M. (2000). Evaluation of Beechfield services: overnight breaks and domiciliary support services for families and children with learning disabilities. University of Ulster/EHSSB, Ulster.
 - McConkey, R., Gent, C. & Scowcroft, E. (2011). Critical features of short break & community support services to families & disabled young people whose behaviour is severely challenging. *Journal of Intellectual Disabilities*, 15 4, 252-268.

- McConkey, R., Truesdale, M. & Conliffe, C. (2004). 'The features of short-break residential services valued by families who have children with multiple disabilities.' *Journal of Social Work*, 4, 61–75.
- McGill, P., Tennyson, A. & Cooper, V. (2006). 'Parents whose children with learning disabilities & challenging behaviour attend 52-week residential schools: their perceptions of services received & expectations of the future.' *British Journal of Social Work*, 36, 597–616.
- McNally, S., Ben-Shlomo, Y. & Newman, S. (1999). The effects of respite care on informal carers' well-being: a systematic review. *Disability & Rehabilitation*, 21, 1–14.
- McConkey, R., Truesdale, M. & Conliffe, C. (2004). The features of short break residential services valued by families who have children with multiple disabilities. *Journal of Social Work*, 4, 60-70.
- Mencap (2010). Still Waiting for a Break. London: Mencap.

MENCAP's (2006). Breaking Point Survey [Online] Available at:

- https://www.mencap.org.uk/sites/default/files/documents/2008-03/Breaking_Point_Families_still_need_a_break.pdf. Accessed: 28th February 2015.
- Mooney, A., Owen, C. and Statham, J. (2008). *Disabled Children: Numbers, Characteristics* and Local Service Provision. London: Thomas Coram Research Unit.
- Mullins, L.L., Aniol, K., & Boyd, M.L. (2002). The influence of respite care on psychological distress in parents of children with developmental disabilities: A longitudinal Study. *Children's services: social policy, research and practice, 5*, 120-130.
 - Neufeld, S. M., Query, B. & Drummond, J. (2001). Respite care users who have children with chronic conditions: are they getting a break?. *Journal of pediatric nursing*, 16(4), 234-244.

- Oswin, M. (1984). They Keep Going Away: a Critical Study of Short-Term Residential Care Services for Children with Learning Difficulties. London: King's Fund London.
- Platts, H., Hughes, J., Lenehan, C., Morris, S. & Flynn, M. (1995). We miss her when she goes away: respite services for children with learning difficulties and additional health needs. Manchester: National Development Team.
- Pollock, N., Law, M., King, S., & Rosenbaum, P. (2001). *Respite Services: A Critical Review of the Literature*. Retrieved from Can Child Centre for Disability Research:

 http://www.canchild.ca/en/canchildresources/respiteservices.asp
- Prewett, B. (1999). Short-term break, long-term benefit: family-based short-term care for disabled children and adults. Sheffield: Joint Unit for Social Services Research, University of Sheffield.
 - Robertson, J., Hatton, C., Emerson, E., Wells, E., Collins, M., Langer, S. & Welch, V. (2010). *The Impacts of Short Break Provision on Disabled Children & Families:*An International Literature Review. Centre for Disability Research (CeDR)

 Lancaster University.
 - Robertson, J., Hatton, C., Wells, E., Collins, M., Langer, S., Welch, V. & Emerson, E.
 (2011). The Impacts of short break provision on families with a disabled child: an international literature review. *Health & Social Care in the Community*, 19(4), 337-371.
- Short-DeGraff, M. & Kologinsky, E. (1988). Respite care: Roles for therapists in support of families with handicapped children. *Physical & Occupational Therapy in Pediatrics*, 7(4), 3-18.
- Sloper, P., & Turner, S. (1992). Service needs of families of children with severe physical disability. Child: *Care, Health and Development, 18*, 250-270.
- Spruin, E. & Abbott, N. (2014). The Evaluation of a Summer Youth Scheme for Children with

- Disabilities. Canterbury: Canterbury Christ Church University.
- Staley, K. (2008). Having a Break: Good Practice in Short Breaks for Families with Children

 Who Have Complex Health Needs & Disabilities. London: Social Care Institute for

 Excellence.
- Stalker K. & Robinson C. (1994). Parents' views of different respite care services. *Mental Handicap Research*, 7, 97-117.
- Stalker, K. (1988). Family-based Respite Care for Children with Severe Learning Difficulties:

 An Evaluation of the Lothian Scheme. *Social Services Research*, *1*, 1-10.
- Starkey, J. & Sarli, P. (1989). Respite and family support services: Responding to the need. *Child and Adolescent Social Work Journal*, 6(4), 313-326.
- Stone, L., Otten, R., Engels, R., Vermulst, A., & Janssens, J. (2010). Psychometric properties of the parent and teacher versions of the strengths and difficulties questionnaire for 4-to 12-year-olds: a review. *Clinical Child Family Review*, *13*, 254-74.
- Swift, P., Grant, G., & McGrath, M. (1991). Parent's views of different respite care services.

 Mental Handicap Research, 7, 90-117.
 - Tarleton, B. & Macaulay, F. (2002). Better for the Break? Short break services for children and teenagers with autistic spectrum disorders and their families. York: Shared Care Network.
- Welch, V., Hatton, C., Wells, E., Collins, M., Langer, S., Robertson, J. & Emerson, E. (2011).

 The Impact of Short Breaks on Families with a Disabled Child; Report One of the Quantitative Phase. London: Department for Education.
- Wilkie, B., & Barr, O. (2008). The experiences of Parents of Children with and Intellectual Disability Who Use Respite Care Services, *Learning Disability Practice*, 11, 29-32.

Zwirs, B. W., Burger, H., Schulpen, T. W., Wiznitzer, M., Fedder, H., & Buitelaar, J. K. (2007). Prevalence of psychiatric disorders among children of different ethnic origin.

*Journal of Abnormal Child Psychology, 35, 556–566.