

Do short breaks make a difference to the emotional well-being of parents raising children with developmental disabilities in rural Australia?

Dr. Kathleen Tait

Macquarie University

Mr. Francis Fung

The University of Hong Kong

Author for Correspondence:

Dr. Kathleen Tait MBPsS

Address for Correspondence:

*Department of Educational Studies
Macquarie University
North Ryde
Sydney NSW 2109
Australia*

Abstract: *Background* This study aimed to investigate the measured impact of short breaks on the emotional well-being of rural parents who were raising a child with a developmental disability in a rural location in Australia. *Method* A total of 49 parents completed the Family Quality of Life survey (Beach Centre, 2005) via postal questionnaires. Seventeen of the surveyed parents volunteered to be interviewed about their experiences of using short breaks. *Results* While all parents reported receiving funding for some version of short break care, in over one third of the cases (n=18), parents did not find the service on offer helpful. As a result, instead of easing these rural parents' burden, accessing short breaks had impacted quite negatively upon their emotional well-being. *Conclusion* Results of this study indicate that a more proactive approach to identifying and meeting the unique needs for short break support by rural parents is required.

KEYWORDS: *respite care; short breaks, family emotional well-being, developmental disabilities; rural Australia*

I. Introduction

For many decades, there has been a widespread assumption that short breaks (or respite care) for family carers of children with intellectual disabilities has a beneficial impact on reducing carer stress, an increased capacity for family carers to continue caring, and for an increased child enjoyment of a wider range of social opportunities (Cowen & Reed, 2002). Historically, the term 'respite care' has been used in much of the literature concerning short breaks for families with a child with an intellectual disability. However, quite recently, 'short breaks' has become the preferred term, partly due to the negative connotations of parents carers requiring respite from their children, and partly because short breaks now encompass a much wider range of supports, than just out-of-home placement in specialist residential facilities (Welch, 2012). As such, the term short breaks will be used throughout this paper, with the exception of direct quotes where the term respite was used by the interviewed participants.

According to McGill, Papachristoforou, & Cooper, (2006), short breaks typically involve the provision of an organized service that takes over the parental role for a short period of time on some regular basis. The child might, for example, spend one weekend each month at a residential care centre, or a staff member of a local support agency (possibly a nurse) might come to the parents' home one day each week to care for the child. Short break services can be extremely diverse, and can vary in:

- 1) Their location: which could include the child's own home, the home of a contracted short break carer, specialist residential settings, or any number of community settings;
- 2) Their duration: which could include anything from a few hours, to an overnight stay, to overnight stays of several days, or even longer if needed,
- 3) Their timing: which could include weekdays, week-ends, evenings or overnight; and
- 4) Who provides them: which could include local authorities, health agencies, and/or a range of voluntary and independent community support agencies (Welch, 2012, p. 453).

Clearly, there are many variations of short breaks available, and each comes with its own financial recompense. Nonetheless, in each case, the common objective is to temporarily relieve parents from the stressful demands of caring for their child with a developmental disability (DD) for a short time, in order to give them the opportunity to lead an ordinary life (Schalock, 2004).

A recent synthesis of findings from Strunk (2013) indicated that short breaks should be used as an appropriate coping strategy for parents of children with disabilities to increase family quality of life, heighten emotional well-being, and to decrease parental stress. These are reasonable expectations, based on what appears to be a logical argument. However, the ability of short breaks to buffer parents from stress and decreased social isolation is predicated upon the parents' access to and utilization of the service (Cramer and Carlin, 2008; Salisbury, 1990). It has been well documented that when a family caring for a child with a disability lives in a rural and remote area, access to community support services, such as social workers, health and education programs, are often in short supply (Gething, 1997; Tait & Hussain, 2015). Providing community support services, including short break service delivery, to rural communities is complicated because the relatively small numbers of people in need are dispersed over large geographic areas (Hussain & Tait, 2015; Vietch, 2008).

While others have attempted to evaluate the overall impact of short breaks on rural families by conducting quantitative meta-reviews of the literature (e.g., Chan & Sigafoos, 2000; Strunk, 2013), these reviews have not addressed the issue of whether the use of short breaks had any significant impact on parental quality of family life and emotional well-being. There is a paucity of qualitative research focused on the characteristics related to the utilization of short break services by families living in rural regions of Australia. If stress reduction is touted as a major potential benefit of short breaks, then it is important to examine whether or not this is a likely outcome for rural parents raising a child with DD seeking short break services. Do short breaks reduce parental stress, improve parental emotional well-being, and increase family quality of life? Or is the strain of accessing acceptable short break services causing more burden to rural parents? Seeking answers to these questions directly from the consumers, may also help to tease out variables associated with better outcomes for rural parents raising a child with DD and this, in turn, may enable support service professionals to design better short break services.

The current paper is part of a larger mixed-methods study on parental perceptions of vulnerability and resilience in rural families living with a child with DD. The impact on rural parents who are currently trying to adjust to cater for a family member with a disability in the face of limited health services has been reported elsewhere (Hussain & Tait, 2015). The purpose of the present study was to investigate parents' perception of short break services and how accessing these services impacts on the day to day experience of raising a child with DD in a rural location of Australia. The data that is presented in this paper was collected via 49 FQOL surveys and 17 qualitative in-depth interviews.

Method

Context

The region under study is known as the New England region of northern New South Wales and consists of large areas of rugged country, as well as an extensive plateau. As at 30 June 2009, the estimated resident population of the New England region was around 6.25% of the total Australian population (Australian Bureau of Statistics, 2009). The region's population is dispersed among large regional towns of 20–40 000 residents, smaller towns of 1–3000 residents, and isolated rural communities of less than 1000 people (Wilkinson, 2014). In addition,

some people live on remote properties (farms) many kilometres from their nearest neighbour, and hundreds of kilometres from towns. One participant of the current study explained that it was a 300 kilometre round trip to the supermarket. Consequently, the study setting covers a large geographically rural region of Australia with a relatively lower population density leading to greater challenges in accessing services. A mixed-method study design was used incorporating quantitative and qualitative components.

Participants

The target population for this study consisted of parents from rural families who were rearing at least one family member who had been diagnosed with a disability between the ages of 3 – 20 years. This age group was chosen as it relates to the school age years and very early post-school years and as a result, should highlight a range of information on short break requirements by rural families.

Data Collection

Three kinds of data were collected. Firstly, a demographic questionnaire was completed primarily by ticking boxes and filling in blank spaces. Parent characteristics sought were gender, age, family structure and annual income information. Child characteristics sought were child's gender, age, and disability. Secondly, data were collected on the parents' perception of their family's quality of life as a direct result of raising a child with ID in a rural community, via the use of the Family Quality of Life scale (FQOL) (Beach Center on Disability, 2005). Finally, parents were invited to be involved in face-to-face, semi-structured interviews in order to add their personal accounts on the nature and perceived helpfulness of short breaks to this investigation. Semi-structured interviews were chosen as a data collection method because they provide an opportunity for participants to address broad topics relevant to the project aims, and to expand on issues arising from these topics (Creswell, 2012, Bryman, 2008).

To maintain anonymity and confidentiality of the participants, a total of 500 survey packages containing a detailed information sheet, consent form, the questionnaire and reply-paid envelope, were sent to local support service agencies, who forwarded the survey packets to the families on their databases. One of the complexities in sending out survey forms through a number of disability agencies is the inherent difficulty of knowing how many survey forms were actually sent out by each agency and whether some families received multiple forms, due to being in receipt of services through a range of service providers. Consequently, it is not possible to estimate the final response rate to the survey component of the study. Of the 80 packages which were returned, 19 (4%) were returned unopened with "address not valid" postal stamps. Of the remaining 61 survey forms, 12 forms had incomplete information, leading to 49 usable survey responses. Consequently, the total number of analyzed FQOL surveys was N=49. The very low response rate is discussed briefly in the limitations sections of this article.

The survey instrument

The FQOL survey consists of five domains, (1) physical and material well-being, (2) emotional well-being, (3) family interaction, (4) parenting, and (5) disability related support. This instrument contains 25 items where participants are asked to rate globally their overall satisfaction with their family's quality of life using a five-point Likert scale with scores ranging from 1 = very dissatisfied, to 5 = very satisfied. The FQOL was selected because of its brevity and its acceptable reliability ($\alpha = .80 - .85$). In addition, this survey is reported to have satisfactory psychometric properties, that is, test-retest reliability, and convergent and construct validity (Summers et al., 2005; Hoffman et al., 2006). It is also important to note that the results of the FQOL survey can be used as outcome measures to evaluate the degree to which policies and supports to families are being effectively applied (Kresak, Gallagher, & Kelley, 2014).

Emotional Well Being

One of the five domains of the FQOL survey, emotional well-being (EWB) is a concept that has been widely researched and can be defined as an individual's global assessment of their quality of life (Cummings, et. al. 2004; Dear, Henderson, & Korten, 2002). EWB is measured from an individual's own perspective and is the evaluative judgment that an individual makes on their level of satisfaction with their life (Diener, 2000). The issues that dominate the EWB domain within the FQOL survey relate to the allocation and delivery of resources and support services, such as short breaks.

The interview

Seventeen (approximately 35%) of the cohort of surveyed respondents (N=49), all of whom had experienced using short break services for their children, took up the offer to have a face-to-face interview. The

interview was designed to obtain general information on issues such as needs for, access to, and the use of, short break services, as well as some general topics on parental adjustment to living with a child with DD in rural NSW. These interviews were recorded and later transcribed, member checked, analyzed and used in an effort to further explain the findings of the FQOL data.

Information obtained from the parent interview (n=17) and the FQOL scale (N=49) was organized, classified and synthesized. Initially, demographic child and parent characteristics were summarized to identify the family context in which the members were functioning. The data have been standardized with a mean value of 50 and a standard deviation value of 10. This means that the data was comparable and that it was possible to rank the data using Skewness values. All data analyses were done using the SPSS version 12. Interviews were analyzed ethnographically for thematic content as a means of providing understanding of these parents' quality of family life experiences (Lincoln & Guba 1985).

II. Results

General description of the parents

Respondents varied considerably in age (range: 23-68 years, mean: 46 years). The demographic profile of the study sample showed that the majority of the respondents (N= 49, 96.1%) were females, predominantly being the mother of the child with DD. With regard to marital status, most of the respondents (84.3%) reported living with a partner. Of the participants who had partners, 58.8% of those partners worked full-time. Family size varied from two people (9.8%) to four or more (81.6%). In terms of income, approximately one third of the surveyed respondents (n=17) reported making less than \$25,000. The majority of the surveyed respondents reported house duties or worked either on a casual or part-time basis.

Description of the children with intellectual disabilities

In the total sample (N=49), 30 (61.2%) of the children in this study were male children and 19 (37.3%) were female children (mean age: 9.5 years). Approximately 12% (n=6) of the children were within the pre-school age range (i.e., 3-5 years olds); 24 (48.9%) were within the primary school age range (i.e., 6-12 year olds), 16 (31%) were of secondary school age (i.e., 13-18 years), and 3 (6%) were of post school age (19-20 years). While the birth order of the children varied, the target child was the eldest child, in over 67% of the total sample (n=33). All of the children in this study (N=51) had engaged in some form of short break experience.

The target children in this study had multiple conditions, many stemming from their primary diagnosis. The two most commonly reported primary diagnoses were Autism (n=7, 13.7%) and Asperger's Syndrome (n=7, 13.7%) followed closely by Down Syndrome (DS) (n=6, 13.7%) and Global Developmental Delay (n=6, 13.7%). In this group of children with DD, 10.2% (n= 5) were considered by their carers to be of average intelligence, while 36.7% of children (n=18) were considered to be below average intelligence. The majority of parents (n=26, 53%) indicated that they just did not know.

Family Quality of Life measures

A statistical and correlation analysis of the main findings of the FQOL data was calculated. Please refer to Table 1. In order to be able to determine the strength of the relationships in this data, (i.e., the effect size), it should be noted that coefficients between .10 and .29 represent a small association; coefficients between .30 and .49 represent a medium association; and coefficients above .50 represent a large association or relationship. Consequently, the results outlined in Table 1 indicate that there is a strong and statistically significant relationship (with p-value < 0.05) on the following domains of the FQOL data for this group of parents:

- Family interaction and Parenting
- Family interaction and Emotional well-being
- Family interaction and Disability related support
- Parenting and Emotional well-being
- Parenting and Disability related support
- Emotional well-being and Disability related support

Table 1 Correlation Table FQOL Results (N = 49)

		Family Quality of Life Domains				
		Family interaction	Parenting	Emotional well-being	Physical / Material well-being	Disability related support
FQOL – Family interaction	Pearson Correlation	1	.755**	.688**	.235	.625**
	Sig. (2-tailed)		.000	.000	.104	.000
	N	49	49	49	49	49
FQOL – Parenting	Pearson Correlation	.755**	1	.759**	.372**	.655**
	Sig. (2-tailed)	.000		.000	.009	.000
	N	49	49	49	49	49
FQOL- Emotional well-being	Pearson Correlation	.688**	.759**	1	.435**	.639**
	Sig. (2-tailed)	.000	.000		.002	.000
	N	49	49	49	49	49
FQOL- Physical / Material well-being	Pearson Correlation	.235	.372**	.435**	1	.249
	Sig. (2-tailed)	.104	.009	.002		.084
	N	49	49	49	49	49
FQOL - Disability related support	Pearson Correlation	.625**	.655**	.639**	.249	1
	Sig. (2-tailed)	.000	.000	.000	.084	
	N	49	49	49	49	49

** . Correlation is significant at the 0.01 level (2-tailed).

Family Quality of Life variables

The participants were asked to rate their satisfaction with their family’s quality of life using the FQOL survey (2005), and the results revealed that these families rated their satisfaction as being between 55% – 65% at or above the mean (50.00) for 4 out of 5 of the FQOL variables (Tait & Hussain, 2015). This indicates that, using the FQOL five-point Likert scale, participants’ were moderately satisfied with their level of family interaction, parenting, physical and material well-being and disability related support items. However, for the emotional well-being (EWB) variable, only 24 out of 49 families (49%) scored at or above the mean (50.00). Explanations of the EWB items will be followed by a descriptive summary of the findings of this study, and

exerts from the parent interviews will be used to highlight participants' perception of the EWB variable in relation to their experiences of short break services in rural NSW.

Emotion well-being

The emotional well-being variable focuses upon the interaction of the person with his or her environment; and its impact is influenced by the recognition that resources and supports from the contacts and individuals' typical environments (e.g. family, friends, neighbours and community), can better enhance overall quality of life outcomes (Schallock et al.,2010).Table 2 outlines a frequency and percentage count for each of the 4 x items in the FQOL EWBdomain. While there was a wide spread of parent perception regarding satisfaction with EWB,it should be noted that more than 50% of respondents indicated that they were either a dissatisfied (score 2) or very dissatisfied (score 1) for Q 3 and Q 13 of this domain (see Table 2). The overall outcome of the rating of items in this domain, indicates that almost half of the participants in this study felt very disappointed with their families' access to support for their child with DD. As a result, it is conceivable that accessing short breaks couldbe another source of stress for these families.

Table 2. FQOL – Emotion well-being (N = 49)

Frequency and percentage count for each question

Question	Q3.	Q4.	Q9.	Q13.
Very dissatisfied	14 (28.57%)	9 (18.37%)	10 (20.41%)	13 (26.53%)
Dissatisfied	12 (24.49%)	10 (20.41%)	9 (18.37%)	12 (24.49%)
Neutral	7 (14.29%)	9 (18.37%)	6 (12.24%)	9 (18.37%)
Satisfied	8 (16.33%)	12 (24.49%)	17 (34.69%)	9 (18.37%)
Very satisfied	8 (16.33%)	9 (18.37%)	7 (14.29%)	6 (12.24%)

The Emotional well- being domain of the FQOL survey has 4 items: Item 1: (Q3). My family has the support we need to relieve stress; Item 2: (Q4). My family members have friends or others who provide support; Item 3: (Q9). My family members have some time to pursue their own interests; and Item 4: (Q13). My family has outside help available to us to take care of special needs of all family members. Questions number 3, 4 and 13 focus specifically on the issue of disability-related support services (i.e., short breaks) as required by rural families who are caring for a family member with a significant disability. While question no 9 refers more specifically to family members' quality of life. To investigate this issue more fully, participants were invited to give accounts of their experience of using short break services via a face to face interview. Seventeen of the surveyed families in the present study accepted this invitation. The focus of the remainder of this paper reports on the perceptions of these 17 participants' short break service experience. The next section gives some insight into why participants may have scored the way that they did on the emotional well-being items.

Item 1: My family has the support we need to relieve stress(Q3)

Parents in the present study were highly critical of the endless rules, assessments, application forms, and the continuous funding procedure changes required to acquire funding. This distress is of major concern given the known barriers to accessing specialized child care in many rural and remote areas in Australia (Judd, 2006). Parents in the present study described how even though technically there was funding available to them, there were constant problems with long and complicated application processes; resulting in parents either not being able to access this money; or there were long waiting periods to get funds reimbursed; or the amount of funding allocated to them was not perceived as adequate for their child's or their family's needs.

We've put him in vacation care and that's had a fairly mixed response. A lot of the vacation care people aren't prepared to take him on once they realise that he's got some sort of disability. And you

know, they're wanting the funding, but they're wanting specialist reports, or they're wanting this and that, before they're prepared to take him on (Interviewee No 7).

We shouldn't have to meet the criteria. If I need it – I should be able to have it. There should be no forms to fill out all the time either. There shouldn't be, "Let's go over it again. Let's see what he's got. Let's do this test. Let's fill this out. No! Let's do it once! We need help all the time. We shouldn't have to fill out, you know date of birth, and this, and that. That's not what it's about. Respite's about the child and the family (Interviewee No 14).

Participants also spoke of the many changes to funding, changes to names of agencies, and being confused by what funding body they were eligible to access. In addition, some parents explained that there were barriers to being able to use what funding was available, in the way that they wanted, in order to meet their families' needs.

You have sort of got to rev yourself up to Oh God not this again. I rang the (Commonwealth name) Respite Centre. I said, We are going to the (coastal area) for an autism conference and can we have the person (to care for child), that we had last time, because she was fabulous. I was told, Oh well I don't know? I said, You guys employed her 18 months ago to do exactly this. What do you mean you don't know? She is like, Things have changed now. Send me an email to (Regional name) Respite Centre. I thought far out! How are you now (Regional name) Respite Centre, when you were (Commonwealth name) Respite Centre? (Interviewee No 5).

Respite doesn't happen, because they don't want to give me the dates... or they can't because there's no workers. Well, why tell me I can get 21 days a year for him, and then not be able to give me the dates I want? (Interviewee No 1).

There is no doubt that families living in rural and remote Australia are subject to geographical isolation. Not surprisingly then, one of the major concerns for the rural parents in the present study was the distance that was required for them to travel to access short break services. The flip side of this problem is the distance required for paid carers to drive out to the family home, if parents preferred to use in-home short break care for their child with DD.

We get 4 hours every 4 weeks. But sometimes you think, Do I really want respite? 'cause you think about the hour trip to and from as well and it's up and down hills and around, and up, and I've hit 'roos before. I'm thinking, ...not really worth it. Why do it? 'Cause the 4 hours isn't enough to go anywhere, 'cause of the distance (Interviewee No 3).

One of my biggest issues at the moment is accessing respite that I think is appropriate. First of all getting workers to come to this area, like getting someone to come to my home and do respite in-home, which is my preferred form of respite, is very difficult. There is not a lot of people that want to travel this far out of town (Interviewee No 5).

Item 2: My family members have friends or others who provide support (Q4)

Past research has suggested that rural parents are likely to experience child-minding differently to their urban counterparts because of the limited availability of informal child care (Bullock, 1988). For example, rural parents are typically more isolated from the usual sources of child minding support; such as close relatives (e.g., grandparents, aunts & uncles), neighbours, close friends, or local community parenting groups (e.g., play groups). Unable to access familiar and/or trusted support, participants in the present study spoke of the difficulties involved in not only employing, but also in maintaining suitable in-home short break carers.

Look you wouldn't know what sort of fruit loop (sic) was walking in off the streets if you put a sign up in a shop window. I know you've gotta have the Police checks and everything else. But you still gotta be careful. I've just put too much into (child) to let, the slightest thing happen now (Interviewee No 6).

The child minder that (child) has gone to over the last couple of years, has given it up. Now there's gonna be the matter of (child) being comfortable to go with somebody else, which isn't going to happen easily. And it's no point sending him to somebody he doesn't know or isn't comfortable with, because then I've got bigger issues when he comes home. It just doesn't achieve anything (Interviewee No 4).

Item 3: My family members have some time to pursue their own interests (Q9)

Families living in rural Australia are also subject to a unique set of living conditions such as limited work opportunities (Novello, Stain, Lyle, & Kelly, 2011); and (as has been the case in recent years) extensive and prolonged drought. The social and economic consequences of a protracted period of drought has become yet another significant stressor impacting on rural families (Dean & Stain 2007). Strained financial resources are often complicated further when only one parent can work due to caregiving responsibilities, as is frequently the case when parents are raising a child with DD. Parents in the present study explained how due to minimal resources there were limited opportunities to pursue their own interests.

A vacation? What's that? (Interviewee No 12).

The result of getting the second lowest level of funding from now on, is that I will probably have to give up my work in order to mind him at home on the days that he doesn't go to Community Participation, which only runs for half a day, 3 days per week. It's less than school hours! And giving up your work is more than just giving up money. It's giving up your sense of self identity, my self-worth... (Interviewee No 11).

Living with a family member with a disability can also influence the psychological wellbeing of other family members, particularly those residing within the same household (Noh & Turner, 1987). While the present study did not investigate the impact on siblings specifically, parents were asked about their perceptions of the impact of raising a child with a disability on their other children and if they were able to spend equal time with their other children? Parents in the present study reported that other family members frequently had to adapt and miss out on planned events in order to cater for the special needs of their sibling.

(Sibling) does feel that he missed out on a lot when he was little, and it's true, he did get pushed aside. He often got shipped off to Nan's, or shipped off to one of his Aunties' houses when we had to take (child) to the city for an appointment or assessment (Interviewee No 17).

Support? Where do you go? Where do you turn to for support? I thought, for this five days we're going to Canberra, I could put (child) into care, which he was happy to go into, and then just the girls and us could have a break. It would have worked really well for everybody. But they can't give me the dates I need. So the girls, and us, missed out again. (Interviewee No 6).

Item 4: My family has outside help available to us to take care of special needs of all family members (Q13)

Some parents explained that even when trained professionals were available, they would shirk their responsibilities, preferring to seek out other family members (frequently the child with DD's siblings) to take on the brunt of the care taking duties. This was frequently the case in situations such as vacation or after school care where, due to limited options, the child with DD and their siblings would have to attend the same centre. Other participants described how they believed that, with the new Government NDIS funding scheme, that the public has wrongly come to the conclusion that these days there are enough support services for families with a child with DD, and that that incorrect perception was distressing.

From the beginning, you know, if (child) needed to go to the toilet or something and needed some help, they'd (vacation care teachers) come and get (sibling) to take her. Or, if (child) was getting upset, they'd get (sibling) to come and settle her down. It's like – She's in year 4, you know, it's not her job. It's your job – please don't do this!. But that kept happening (Interviewee No 8).

I think quality of life is hard because people think, Oh, you can get respite now. But we don't! (Interviewee No. 11).

Parents' low use of short break services

Several studies have indicated that parent utilization of short breaks is low (Edgar, Reid, & Pious, 1988; Marc & MacDonald, 1988). The present study determined a similar result. Table 3 indicates that only about two thirds of the families (67.4%, n=33) in this project identified that they were accessing some form of short break service. Twenty-two (44.8%) families indicated that they were utilizing out-of-home short break services; 9 (18.4%) families were receiving some sort of in-home short break care; while 18 (32.6%) families were not using any government funded short break service at all.

Table 3: Short break service support usage

Type of Short Break Support	Hours received Mean (SD)	Additional Hours requested Mean (SD)	Families receiving support Number (Percentage)
In home care short break service	0.81 (2.85)	1.66 (3.95)	9 (18.4%)
Out of home short break service	3.33 (8.8)	3.27 (5.64)	22 (44.8%)

Parents in the present study gave numerous reasons as to why they did or did not use short breaks. In a recent study conducted by Novello, Stain, Lyle, & Kelly, (2011) parents indicated that they were fearful of the level of care that their child would receive in respite care services. This sense of trepidation was supported in the present study. Here the interviewed parents discussed their fears not only about the quality of care, but the suitability of activities on offer at the various short break centres. They were also apprehensive about the level of comfort, safety and activity engagement that their child would experience whilst in the care of others.

People just assume it is fine and that a break will be really good for you. My son is going away to live with strangers for a week..... and I am not good with it. He is my eleven year old. And to live in this place that has got no carpet on the floor, almost like a very sterile environment, and to not really be doing anything very interesting... (Interviewee No 5).

The one in (Area 1) is very different from the one in (Area 2). The respite service in (Area 1), it's just a house with a bit of a yard, and it's a pretty boring place for a group of kids. Even though they have a lot of inside stuff, (child)'s a very outdoorsy sort of person. But the respite service in (Area 2), they have a backyard stretched from here to China, and it's got chooks and birds, reptiles, ducks, a dog, and a cat. They've got things to do, and he was relaxed and happy. He loved it there. Whereas the one at (Area 1) - I don't like, 'cause he came home with bruises, and no thongs, and not being washed and they went to the creek up there, and he was just sent home covered in bites (Interviewee No 14).

Some parents discussed the extra stress and worry that they felt when their child was attending short breaks. Most were concerned about staff understanding their child's individual needs, and worrying if their child was happy. Several parents gave accounts of situations where their children had been left to their own devices while they were at residential short break care.

We had such a bad experience at (short break centre) where (18 yr child) would take games, having been told by a case worker Oh, they'd love to have you, because you can play games and things. Well actually, they'd sit them in front of the television and go out and sit on the verandah and have a smoke and a cup of tea with the other worker. So (child) would behave terribly, to get their attention, because she'd been told that they'd play games with her. She took her UNO with her every time, but no-one ever played a game with her. No-one. I don't want somebody sitting out on the verandah having a smoke, when my daughter's inside wanting someone to give her some company. That's not respite for me (Interviewee No 8).

First time I went for an interview at (short break centre), we put him (child) in front of the television and I went to take a video to put on for him to watch while we were going filling in paperwork. I thought at that time Wiggly Safari wasn't really an appropriate thing for him to watch at that age (12 yrs), but I knew that it would keep him calm while we were away. I was being helpful. The carer said to me, Oh we have already got that, in fact they have been watching it all weekend. I was just sick at the thought that, (1) they watched the same thing over and over again for an entire weekend, and (2)

that it was a kid's program... particularly for the young man and the 40 year old woman with limited speech. These people had just been parked (in the TV room) and I thought, These are adults! It wasn't a conscious thing, they had no awareness of what they were doing... and that is also horrendous to me. So (child) only uses the (short break centre) when we feel we have no other option (Interviewee No 3).

In Gilmore's (2002) study, parents reported that short breaks were a distressing experience for the family because of their concerns regarding the quality of care delivery and the poor personal management of the child with DD. As a result, a support service that was designed to reduce family stress, may in fact, in certain situations, be creating stress. This appeared to be the case for several families in the present study.

They don't manage her well, so she has these terrible eruptions and then they ring us to pick her up ...and that sets a pattern and now she knows that's how she can get out of a situation,(Interviewee No 8).

Like, they have people who are just not trained. For instance (child)'s on medication (for behaviour) in the mornings. Sometimes he does get sick from it – it's a side effect from the medication. One time he went to respite, he got sick in the morning. They didn't ring us up to say Look, he's been sick. He's had the tablet or whatever, what do you want me to do? Do you still want us to give him this tablet or not? Instead, for those two days he had no medication. None whatsoever! He came back and for the whole week after that, he was absolutely crap (sic) because he was just so full on (Interviewee No 14).

A study by Hartrey & Wells, (2003) indicated that the short break experience may not always be positive. Several other parents in this study reported that their children had reacted badly upon returning from short break care and this had affected their future use of those facilities. Others spoke of an inequality of access to short break care, and just not being able to request access to care, when it suited the family.

I just feel sick at the thought. Respite needs to be respite, you need to feel comfortable about them being there and he is happy and safe. I don't feel like he is treated as an individual there and I know he is distressed. He came home one time and he was just hitting himself the next day, all day. And we just realised that we just weren't going to do it again.(Interviewee No 3).

Like they made this rule that you can't use it (short break care) on Sundays. Well, I only want two hours on Sundays, because the pay rate (for my work) is more. You know, I want 2 x hours on Sunday, rather than 4 x hours on Monday. That is more important to me. So they say, Yes, it's for you to use. This is your service...but a lot of services are not matching our needs particularly well (Interviewee No 9).

The results from studies conducted by and Ashworth and Baker, (2000) showed that some parents using short break care experienced guilt or increased stress. One parent in the present study explained how she avoided using NDIS funding for her own child's short break care, because, due to the lack of carers in her area, she felt that she might be taking away services from a more deserving family.

I've been using it maybe once a year. The only thing that I can access is in-home emergency care and a nurse comes to my home for 5 hours. I know that I'm entitled to 10 x hours a month. But, I feel like maybe I should only use it in extreme situations. It makes me feel a little bit guilty, because you kind of think, maybe some other people have more emergencies?(Interviewee No 16).

Turning 18 years is often a reason for great celebration in a family. However, if one is raising a child with DD, then this milestone can have alternate effects on the family. Several parents in this study explained how they were worried about the loss of funding for support services once their child turned 18 years, because that would result in a reduction of their child's short breaks. Another participant explained how the questions on the post-school assessment application form for her 18 year old child were not only inappropriate, but in some cases, barely different to the questions asked when applying for mature aged adult care.

I've been able to access Young Carer's Respite, for (child) for after school care and that meant that I could work for two full days. I don't think that will be available once she turns 18 yrs. So, suddenly, what happens? She's older. She's had all these things to do and suddenly they won't happen. So, leaving school? You're left in a situation of either funding it yourself, but you can't work more! So, what do you fund it with? And, (child)'s carer's have always been her friends. Suddenly you take

them away. So, I'm not looking forward to school finishing, because at least there was something five days a week that was useful and often happy (Interviewee No. 8).

I've done an ACAT Assessment for my 84-year old father and a Post-School Assessment for my 18-year old son (with severe autism) and they were both almost, the same questions ... to the point where I filled in the questionnaire for (son). One of the questions was, Does the 'Client' - note! no longer a student, even though it's the Department of Education doing it. Does the 'Client' have any dangerous behaviors? For example; Smoking in bed. Now, not many children with autism smoke in bed when they live at home. (Interviewee No 11).

In several cases, while parents had access to funding for in-home short breaks, they could not find anyone to employ to be a carer for their child in their local town. Another parent explained that while she had found a suitable carer, the lengthy spacing between in-home care visits caused the child undue stress, which resulted in this family returning their funding to the Government.

I tried respite. But that wasn't really working because the lady could only come once a month, and because (child) only saw her once a month, he didn't develop a bond with her. Even though (child's) very social and everything, it takes him a long time to get used to someone. I just went and said to them, I don't want to use respite (Interviewee No 15).

Being unable to find suitable short break care for their child with DD while they were young, meant that families filled the care gap. But what of the future? Many participants in this study voiced their concerns regarding the future care arrangements for their adult child with ID when they were no longer able to do so.

The future? I'm dreading it. Absolutely dreading it. Who's still gonna be looking after him when you know, I'm in my late sixties? early seventies? (Interviewee no 6).

I can't imagine a time when he's not gonna need support. And the pressing issue is - we don't know when we're going to leave this earth. What happens when we're not here? Just because you have to face it, that doesn't mean you can plan for it... you can't! (Interviewee no 16).

When asked what sort of changes to accessing funding and support would help, one participant's response seemed to cover all of the issues that the other parents described. This parent described the stress of first being made aware of her child's disability, her initial reaction to support service providers and how a different approach would be more useful to families raising a child with DD.

Service provision? Where do I start? Make it simpler. I mean not everybody has a bloody (sic) university degree and can understand all the jargon that goes with it. In terms of getting access to the respite services, you have to jump through so many flippin' hoops! There's so much red tape to go through and it should be very simple. Well, you've had a child that's been diagnosed with a disability. That is gut wrenching...that is soul destroying. You're going through an absolute period of grief and mourning for the child that you should have had. And yes! eventually... you learn to accept it...but at that point in time, when you most need those services and you're grieving for this child and for everything that you've lost, you can't see that. You can't see outside of this box that you're suddenly been put in and you really don't need someone shoving this flippin' great big pile of papers at you saying Here read this. This is all the hoops you need to jump through. They should be embracing you and going, Okay, this is what we're going to do to help you. Not going, here sign this, sign this... and Oh! you're going to have to wait 6-12 months for this and this. Instead, they could explain to you that it's a period of grief, it's a shock, and once that wears off, then you will have a million and one questions. But instead, you're left going, Who do I talk to? I don't know who to talk to? I don't remember!!! So, having the information out there of the (funding) schemes that are available would be a huge thing. Even if you just have a little pamphlet that says, Okay, if you need help with travelling expenses? This is who you call. If you need help with accommodation? This is who you can call. That sort of stuff (Interviewee no 1).

III. Discussion

While disability services may have been founded on well-intentioned assumptions, it is important to keep challenging those assumptions, even if it means challenging the continued provision of that form of service. This paper has set out the assumptions underlying short breaks and reviewed the emerging evidence in the area. In addition, the current project has addressed the very important concept of short break support for carers of children with intellectual disabilities and reports on whether short breaks actually improve quality of life for those parents living in rural Australia. Some parents reported that the short break centres were located too far away from the family home. Others explained that there were no in-home carers available in their area. Further the rationing of short break services caused some families an inequality of access. As a result, instead of easing the parents' burden, accessing short breaks impacted quite negatively upon the emotional well-being of these rural families.

Before summarizing the issues raised in this investigation, it is important to address the limitations of the present study. First, the sample was small and replication with a larger sample would increase confidence in the findings' generality. Secondly, it should be noted that parental accounts may not represent the actual short break support provided. Clegg and colleagues (2001) noted this in a comparison between parental and professional reports. Clegg suggests that this may reflect a discordance between what is offered and what parental expectations of, or beliefs of, what short break care is. Also, consideration needs to be given to the fact that the parents who did not request to be interviewed may be the parents who are most burdened by the care-giving task. They may not have had the time, energy or motivation to engage in a face to face interview, or they may be disillusioned by short break care in general. Alternatively, the reverse might be true. That parents who were most satisfied may have felt that they had little to contribute and it was those parents with a negative experience who were most likely to respond. Nonetheless, this study is an important contribution to the concept of quality of life in the Australian context for parents raising a child with DD in this rural region of NSW.

Chan & Sigafos (2000) advocate that if short break services are to meet the needs and expectations of families seeking to access them, then studies should include a focus on quality of family life outcomes. When the level of stress is reduced, it is anticipated by many, that parents and carers should enjoy a higher quality of life and would then be less likely to seek full time out of home placement for their child (Parker et al, 2010). However, the results of this study and that of Redmond & Richardson (2003) suggest that much of the stress and burden experienced by the caregivers of child with DD is related to inadequate, uncoordinated and hard to access support services. The comments and perceptions about the inadequacy of accessing funding for and the quality of short break services to the rural families in this study further indicate that such services to rural Australian families are currently not adequate to meet the needs of their child with DD.

Clearly, the unique aspects of short break care for rural families caring for a child with ID are quite poorly understood. At the moment, the one size fits all approach to short break service provision is not adequate to meet these rural families' needs. Bringing these issues to light creates the potential to address the unique needs of rural families, improve the provision of short break services, enhance the quality of life of those who can benefit from short breaks, and assist support service staff to work better with family members who live in rural and remote locations. Parents of child with DD are a powerful source of information and support service providers should take into consideration their perspectives when designing, funding and distributing short break services. One of the participants of this study describes, in her view, why the current one size fits all orientation to short break service provision is inadequate:

I think one of the biggest problems with policy and service provision is that each special needs person is just that – they have their own special needs. And I just don't think that anybody sits down and looks at my child as to who she is, and what she needs. She's a person with a disability. But somehow there's this generic, this is what happens for people with disabilities. Instead of... all the disabilities are so different. It has to be specific to their individual needs, not just generic disability services! (Interviewee No. 8).

Caring for a child with a significant impact intellectual disability can be extremely exhausting for all family members. As a result, the concept of short breaks was designed in part, to give parents a break. However, when a family caring for a child with a disability lives in a rural area, access to such services can be in short supply. Although the results of the present study are related to the rural context, they could easily be applied more generally to any parent raising a child with DD and their experience of seeking short breaks. Results from the present study indicate that a more proactive approach to identifying and meeting the individual need for rural parent short break support is needed. It is also recommended that rural community support providers seek to

evaluate the effects on, appropriateness for, and acceptability of, its short break services at the individual level. Additional research is needed to address these limitations. Regrettably, investigations into the adequacy of short break care services, is regularly overlooked within the literature.

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Declaration of interest statement

The authors and associated staff have no conflict of interest with any funding agency or in relation to use of certain survey tools. All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. This study has been independently reviewed and approved by the HREC of the associated University.

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