Family life and the impact of previous and present residential and day care support for children with major cognitive and behavioural challenges: a dilemma for services and policy

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Abstract

Introduction Since the development of inclusion and integration, parents have increasingly become the major, and sometimes the only, carers of their children with disabilities. Many families speak of stress and frustration with service and community support, and some have turned to residential and specialised day care services to overcome challenges. The need for, and experiences of, such services needs to be examined not just in terms of the child but also in terms of family impact.

Method The study involved interviewing parents on a 1:1 basis and in a focus group to examine the perceptions of family life, along with their later experience of full-time day and residential care. The children had multiple diagnoses of intellectual disability plus major challenging behaviour.

Results The results describe the major challenges facing families when the children spent most or all of their time at home. This contrasted starkly with the changes in perceived family life once the children were in residential care and day support. Improvements in behaviour of the children were noted and children began to return home for periods of time. Parent noted increased stability of family life, involvement of siblings in more normal community life and increased opportunities for spouses to function more effectively in one or more life domains. Family members perceived a major improvement in overall quality of life.

Discussion The results are consistent with findings in other family quality of life studies in terms of family experience, and the types of challenges faced when the child was at home, including when excluded from the regular education system. Extensive support in raising children is required by parents and without this there is a deleterious effect on family life. Many families experienced exclusion within their home communities. Full-time day and residential support were provided, allowing the family to function more effectively and later to provide a more natural home environment for the child. The article raises questions of policy concerning family well-being, as well as the needs of the child.

Keywords care & support, challenging behaviour, family, home & residential, intellectual disability
Introduction

A growing issue in the field of intellectual disability (ID) is the importance and desirability of supporting families who have a child with complex ID's. The challenge appears to represent a critical component of service delivery both nationally and internationally (Turnbull et al. 2004; I. Brown et al. 2006; Wang & Brown 2009; Zuna et al. 2009).

The demise of many large institutions, the application of normalisation and the requirements of inclusion have brought many positive changes in the development and performance of persons with ID's. At the same time, there has been a change in the number and types of individuals requiring services. Institutions initially included a large proportion of individuals with mild and moderate ID's, but over the years many of these individuals have been absorbed into the regular services for the general community. There are also an increasing percentage of individuals within service systems who have multiple diagnoses and severe physical medical and/or behavioural needs. Autism spectrum disorder (ASD) is increasingly being diagnosed (Rutter 2005; Baron-Cohen et al. 2009) and foetal alcohol spectrum disorder is now ‘the leading nongenetic cause of intellectual and developmental disability in the Western world’ (Nulman et al. 2007). All of this raises many challenges for families and services (O’Leary 2004).

Frequently, children with severe disabilities, including those with extremely challenging behaviours, now live in the community and are cared for by their parents and attend regular or special education classes. Sometimes, as in the case of the present study, many of the children have been rejected from both normal and special school systems as they are regarded as unmanageable, and there are many reports relating to challenges in family life as individuals try to cope with multiply disabled children within the home (Herring et al. 2006; Ylven et al. 2006; Werner et al. 2009).

Some parents place their multiply challenged children into specialised day and residential programmes catering for special types of disability such as Prader–Willi syndrome or autism spectrum disorder. Some organisations with worldwide services, such as the Camphill Movement, Brothers of Charity services and Jean Vanier homes, run such programmes and cater for these needs. They are, in terms of Western ideology, sometimes regarded as exclusive environments where parents may at times be advised not to place their children. Yet, where there are multiple stresses it can be argued that aspects of such programmes can meet important needs. Furthermore, it is pertinent to raise the issue as to whether, in families facing extreme challenges, the home becomes an exclusive environment, both internally and in relation to the surrounding community. The issue presented here is neither whether inclusion and normalisation are important nor whether large-scale institutionalisation is inappropriate, but to pose questions about the methods by which families, who are greatly stressed and in danger of breaking down, may receive support for their child with disabilities which, at the same time, enables family life to be stabilised so it becomes once again an inclusive situation.

The present article examines, in the context of quality of life, some of the family implications of care and support in a specialised day and residential setting for children who show both cognitive disabilities and extreme behavioural challenges. Quality of life as an approach to intellectual and developmental disabilities has been developing over the past 30 years. Initially, it was directed towards individuals with ID's and was formulated around a number of concepts and principles [e.g. values, self-image, choices, rights (see Schalock et al. 2002)], which led to practical implications (Brown et al. 1992; Goode 1994). Later, it was recognised that many of the quality of life concepts could be applied to the issues of family (Turnbull et al. 2004). It was important to consider the individual with a disability, but also the quality of life of the family members who were now, in increasing numbers, looking after children in their local community. Inclusion of children with ID's has been seen as important, but how has that inclusion affected families? As Brown & Brown (2003) point out, within communities and family living all sorts of exclusion, and therefore dissatisfaction, might come about. In order to examine these issues further, I. Brown et al. (2006) developed the Family Quality of Life survey, which examined nine domains of quality of life (such as health, services, community). The results from research in a variety of countries have illustrated some of the challenges facing many fami-
lies around the world who are carers of a child with an ID (Brown 2010). It is apparent that there is much variability between families, and that issues relating to type of diagnosis, health and behaviour are very relevant in terms of community acceptance and family opportunities. For example, R.I. Brown et al. (2006) demonstrated differences in domain satisfaction between three types of families, those without a child with a disability, those which included a child with Down syndrome and those where the child presented with autism. This order of the families was associated with increasing dissatisfaction with family life, particularly demonstrated in the family life domains of services, community, employment and educational opportunities for family members and this included overall enjoyment of life.

The present study aimed to investigate aspects of these domains in families where the children were not just intellectually disadvantaged but also presented with major behavioural issues, and to examine how quality of life of family members might differ between pre-admission to Camphill School Aberdeen (CSA) and post-admission, that is, when the child was in CSA. Since children spent the vast majority of time in the parent home and local community prior to admission to CSA, and then spent the majority of the time in CSA post admission, the impact on family quality of life could be contrasted. In this study two aspects are considered: the impact of changed support on families before and after admission to CSA and the nature of changes to the children’s behaviour over the same time periods.

It should be noted that the article forms part of a wider study examining the effects of care and support in a largely residential setting with a number of group homes run by CSA in the suburbs of Aberdeen, Scotland. The full study was carried out due to the need for a description of the possible effects of major road developments on the lives of the children in residential and day care at CSA. The first author recommended that in order to assess possible impacts, the perceptions of family members should be examined in relation to the changes as a result of the children being at CSA. The full study involved a wider range of questions relating to services, geography, views of frontline and managerial personnel and the possible effects on the living conditions for the children if a proposed dual carriageway (freeway) were built near the agency’s facility. The current article presents that part of the study relating to parent perception before and after admission of their child to CSA, along with the perceived changes in child behaviour. The study provided an opportunity to involve both mothers and fathers in relation to family life, although it had the disadvantage of being carried out when parents were concerned about the future of their child and their families given the likelihood of major road development. Despite this complexity, the parents gave such clear accounts of the family living conditions and the changes in their child that it was thought appropriate to report the findings of these aspects of the full study (available through Camphill, http://www.camphillmedical.org.uk/downloads/Brown_full_report_2006_updated_2008.pdf).

The article reports families’ perceptions of family functioning between pre-placement and placement at CSA. It also details the families’ perceptions of any major changes in their children’s behaviour during this process. For a detailed description of Camphill history and programmes, see Jackson (2006).

Study questions
The specific questions addressed in the present article were as follows:

- What were the perceptions of parents about family life prior to admission? This included the quality of life of the parents and other members living in the family.
- What were the experiences of the parents in terms of family life after placement?
- What were the perceptions of the children’s behaviour prior to admission as stated by the parents?
- What were the present perceptions of the parents about their child’s current behaviour?

Method
Participants and procedures
Parents of children with multiple diagnoses who had been placed in full day programmes at CSA were interviewed either on a one-to-one or on a
focus group basis. There was no overlap between the two parental groups. Parents were asked whether the interviews could be recorded and all agreed. In addition, the interviewer (R. I. B.), also with agreement, took written notes to help deal with any lack of clarity in recording. Names were deleted from the tapes to preserve anonymity. The tapes were transcribed and randomly checked for accuracy. The transcriptions were then sent for independent analysis to an impartial colleague (N. S. J.), who was not present at CSA and did not know any of the parents or the children.

The individual interviews and focus groups were semi-structured, and the researcher encouraged a free flow of commentary and only interrupted to follow up a statement or to seek clarification. The topic guide covered broadly the following areas for parents/primary carers:
- background information on participant, their family and their child at CSA;
- life prior to their child coming to CSA and impact on participant and their family life;
- family life since child had been attending CSA; and
- changes noted in child behaviour.

The researcher gave oral information as follows:

I’m trying to find out what life was like for you as families before Camphill, what it’s like now that your child is in Camphill; what are the changes, if there are changes, caused by Camphill. Things that work/don’t work.

Let’s start at the beginning again. Tell me what life was like for your family, for yourself and for your child, before your child came to Camphill? And for any siblings, that’s important too.

Child sample

During the period of the study the total number of pupils attending CSA averaged around 83 pupils. There were 23 day pupils and 60 were residential. Twenty of the residential pupils were weekly boarders and 40 ‘full residential’ in term time.

Some of the children who were ‘full residential’ had visits home for special occasions or weekends. Most returned home for vacations.

The families of 23 children agreed to participate in the study, representing just over a quarter of the children’s families. The majority of the children in the study were at the time in full-time residential care at CSA and received active, full-time day programmes. The children’s average age was 12.7 years with a range of 6–19 years. Their period of attendance at CSA was 4.7 years, with a range of 1–13 years. Seventeen of the children were the subjects of individual parent interviews, while six children were the children of parents in the focus group.

The primary diagnoses of the children of the parents selected for the study were based on records from Camphill medical practice NHS (S. G.). In the sample of 23 children, there were a substantial number (17 of the 23) diagnosed as having IDs. There were 16 children with ASD, two of whom had Asperger syndrome. Three children had Down syndrome, two of whom also had diagnosis of ASD. Three children had diagnosed psychiatric disorders, including obsessive compulsive disorder (OCD). There were single cases, each of attention-deficit hyperactivity disorder (ADHD), CHARGE syndrome, Fragile X, foetal alcohol syndrome, Pallister–Killian syndrome and Rett syndrome.

The children had a variety of compounding conditions (see Fig. 1).

Anxiety occurred in almost all the children (21 children) and two children had been diagnosed with depression. Sleep problems were common (17 children) and a significant number suffered from food and other allergies of which 10 were food-related. Eczema, epilepsy, asthma and obesity were further compounding conditions.

The children also had a variety of functional difficulties. Most children (21) had speech and language impairments, which were rated moderate to severe. Equally prevalent were gross and fine motor skills impairments, ranging from mild to moderate. Emotional and behavioural difficulties were a common feature in the full sample. Physical difficulties were somewhat less common but still occurred in one-third of the children, and there were children with both visual and hearing impairments.

The majority (21) of children had sensory hypersensitivities, with most children displaying multiple hypersensitivities. Most common was sensitivity to people, strangers and noise. Sensitivity to visual stimuli was also prevalent and over half of the children were hypersensitive to traffic movement.
Hypersensitivity to light occurred in over half of the children (12 children), with a similar number displaying touch, taste and smell hypersensitivities. Five children were hypersensitive to animals. Such sensitivities resulted in abnormal and/or extreme reactions and behaviours in a wide variety of everyday settings and encounters, as well as increasing anxiety, making life very difficult for the child and those around them.

Parent samples

The participants for individual interview and focus groups were selected at random modified by parent availability. Parents were contacted in strict alphabetical order and asked to consider participating in the study either with individual interviews or in focus groups. The choice was left with them, although parents at a distance were offered and selected a 1:1 interview by phone.

Altogether, 19 parents (17 families) were involved in the 1:1 interviews. In two cases, both parents were interviewed. There were 12 mothers and seven fathers. The above included one foster and one adoptive mother. One of the mothers was divorced and there was one other single parent.

Seven other parents participated in the focus group. The parents represented six children and five families. Two sets of mothers and fathers were present. One family had two children with major disabilities attending CSA.

All but two of the parents were in the age range 35–50 years. One younger parent was in the mid 20s and another parent older than 50 years. The social economic status of the families was judged through low, medium, high with approximately equal numbers in each of the three categories. Likewise, final educational levels ranged similarly between school, college and university. There were a total of 36 siblings ranging from 0–4 in these families.

The interviewee determined the interview duration. The primary reasons for variation were availability of interviewee, time and the desire of many parents to talk at length. In the focus group, which continued for over 2 h, parents noted that this was the first time they had all come together, and found this helpful and supportive. They indicated that they would like to have further meetings run by CSA.

Analysis of results

One-to-one interviews and the focus group were analysed independently. The method of analysis constituted a mixed quantitative and qualitative approach. The first researcher (R. I. B.) set out a framework for a qualitative analysis, but allowed for additional categories to be added by a qualified research colleague (N. S. J.), so that an open system could be maintained in capitalising on content categories. It was possible to categorise statements and frequencies in the case of individual interviews. The focus group data were included to see whether similar trends emerged independently from the 1:1 interviews. Because the focus group spent considerable time on other aspects of the original project, the two groups are

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primarily used in this article to note whether similar types of categories emerged from both groups concerning individual child behaviour and family responses. Participant comments are provided from both groups.

The statements recorded were grouped and categorised under pre-admission and present family themes and, separately, pre-admission and present child behavioural themes. Main themes were expanded as the need arose and several subthemes emerged from the data (e.g. impact of behaviours on the families, subthemes: impact on marriage, siblings). The presence of themes and subthemes, along with their frequencies, were entered into an Excel file. Each entry was re-checked with the print copy of the transcript analysis.

Ethical issues

Prospective study participants were supplied with basic information, which included the reasons for the collection of data, the nature of the interview and focus group, the observance of confidentiality (no names of adults or children to be used in published documents), the right of the participant to terminate any interview or focus group or to decline to answer any questions. Parents understood that the research might be published in various reports and articles and gave written permission for this to take place. The researcher (R. I. B.) asked parents whether the interviews could be tape-recorded. Furthermore, all tape recordings were labelled by code and kept separate from the list of names in a secure environment.

Ethical approval was gained through an independent ethics committee at CSA involving external reviewers. The research design was developed by the first author along with the overall structure of categorisation of information although the allocation to specific categories was carried out independently of CSA by N. S. J.

Results: quantitative and thematic information

Child’s behaviour: prior to Camphill School Aberdeen

One-to-one interviews

Parents expressed concern about a wide range of issues relating to their child prior to admission to CSA. These were diverse covering physical, emotional, psychological, social and educational aspects of the child’s life. Figure 2 shows the types of behaviours that were of particular concern to parents and the frequency with which parents commented on them.

Focus group

Parents from the focus group described a similar range of concerns, and although not analysed numerically the main categories are shown below. These show a high degree of consistency with those from the one-to-one interviews and were classified into 12 themes as follows (child’s behaviour prior to CSA):

![Figure 2](https://example.com/figure2.png)
• difficult to manage;
• unpredictable and uncontrollable;
• negative reaction to change;
• anxious/panicky;
• no sense of danger;
• aggressive;
• destructive;
• self-injury;
• tantrums;
• runs away;
• poor social interaction; and
• noise-sensitive.

These categories are later exemplified and lent depth through excerpts from the parents’ narratives which illustrate the severity of the issues.

Impact of child’s behaviours on family: prior to Camphill School Aberdeen

One-to-one interviews

The impact of the behaviours outlined in the foregoing section was not limited to the children themselves. Figure 3 gives the range and frequency of response from parents regarding the impact of their child’s behaviours on the family prior to attending CSA.

Focus group

The focus group categories relating to family life prior to their child attending CSA fell under nine major themes as follows:
• no proper child support;
• no appropriate family support;
• life focussed on child with special need;
• work and employment goals disrupted;
• no social life;
• no respite;
• restricted outings for family;
• restricted visitors to home; and
• negative impact on siblings.

Changes in the child since starting Camphill School Aberdeen

One-to-one interviews

Figure 4 provides a summary of the categories and the frequencies of parents’ comments on the changes in their child since starting CSA in comparison with children’s behaviour prior to CRS involvement.

Over half of the parents noted overall and positive changes in their child, and highlighted that they viewed their child as contented, comfortable and happy. No negative changes were reported, and the further categories indicate the specific areas in which positive change was noted. Although no decline in behaviours was reported, under some categories one or two parents indicated no change. It is interesting that half of the parents commented on their child’s increased independence. For some, this appeared to be related to the environment of the CSA campus, where quietness, open space combined with safety gave their child freedom to explore. Around half of the parents observed better communication by, and with, their child. This seems to have had positive consequences for improved

Figure 3 Impact of children’s behaviour in family before Camphill School Aberdeen: parental concerns (based on 1:1 interviews, n = 17).
behaviour and a perceived improvement in their quality of life, through an ability to convey their wants and needs.

Focus group

Focus group parents also commented on positive ‘noticeable changes’ in their children and highlighted a similar range of improvements:

- calmer;
- happier;
- improved coping ability;
- reduced unpredictability;
- reduced aggression;
- improved socialisation;
- able to benefit from education;
- increased independence;
- improved communication;
- improvement in health: sleeping and eating;
- reduction in destructive behaviours; and
- increased self-esteem.

Changes in family life

One-to-one interviews

Figure 5 represents parents’ views about changes in family life now that the child has spent some time at CSA.

Parents indicated changes that took place in terms of their experience of family living. There were positive changes in family relations with over half the sample noting relief, being more relaxed, along with improved family relations. Parents also indicated that there was a positive effect on siblings. Due to improvements in the child’s behaviour, nearly half of the parents felt they were often able to enjoy the time that they had with their child with
a disability. When the child came home for periods, a similar number of parents seem to enjoy having them at home and noted increased quality of the time spent together. Being able to enjoy time with their child appeared to be associated with reduced guilt and generally improved family relationships.

**Focus group**

Focus group parents expressed fewer comments on home life, concentrating on the improvement of the child. There was a sense that family life was less restricted while the child was at CSA, and when the child was at home the family could function more normally. The following family themes emerged:

- **general improvement**;
- **improvement in family life when child at home**;
- **improvement in family interaction**; and
- **improvement for siblings**.

**Results: qualitative commentary**

The following represents comments from the parent in 1:1 interviews and the focus group. The comments represent aspects of the child’s behaviour, their siblings and family in general as well as responses in various environments.

Initially prior to admission parents noted as follows:

He gets aggressive towards himself, he bites himself, he strips, he will throw tantrums, throws things he screams because he cannot express himself very well. (F)

He would bite his thumb almost in half, he can’t communicate. (F)

He showed distress by behaviour and his health deteriorated. (F)

If someone was working with a drill [son] would become very hysterical, very upset, it would just really destroy the quality of life he has at the moment, his quality of life is very important. (F)

Three comments, which are typical of the group, underscore some major concerns regarding the impact on family life:

My wife and I were shattered. We used to take night shifts. Sit beside her room over night. And when you’re at full-time work you can’t do night shift and then go do a day shift. (I)

We just wouldn’t go out anywhere. (I)

We have adapted our house and constantly are changing things as [he] discovers that he can – whatever, like pulling a light switch or dimmer switch off and throwing it away. (I)

The effect on other family members was also frequently noted:

So this [the child’s destructive behaviour] had an affect on his brothers. He has two brothers . . . obviously they were being disrupted and their pattern and quality of life has been quite severely impacted upon. (I)

The [Sibling’s] friends have grown up being accustomed to finding the (room) doors locked. (I)

My wife’s parents, nothing to do with who they are, didn’t understand the problem. (F)

Family freedom and choices were thus significantly impacted upon, with disruption and restrictions affecting day-to-day functioning and social interactions whether in the home or community.

Parents indicated changes that took place in terms of their experience of family living once the child went to CSA. The positive changes often involved everyone in the family. Frequently, the parents mentioned that family and parental relations were improved and parents felt more confident when their child had been admitted to CSA. Children returned to the family home on a flexible basis related to improvement as the following comments indicate:

She is home for four nights and resident for three nights. (I)

He’s been in Camphill 2 years, and a weekly boarder. (I)

He stays with us at weekends. (I)

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1 Camphill School Aberdeen (CSA) is the local name for the organisation but parents use the generic organisation ‘Camphill’ in the interviews.

2 Comments provided by parents (I = 1:1 interview; F = focus group).
Due to improvements in the child’s behaviour, parents felt they were now often able to appreciate the time that they had with their child with a disability. For example, when the child came home, parents and other family members seemed to enjoy having them at home and were aware of the increased quality of the time spent together:

Now when he comes home at the weekend we can enjoy having him home because you know that’s the time you spend with him. (I)

In addition, for some parents, improvements in their child’s behaviour meant that when the child was at home the whole family could at times go out together:

It’s just given us a total different way of life. We never went out as a whole family before. (I)

Siblings and parents had improved sleep at night and there was respite from the physical care of the child:

I can sleep! Sleep! I can go to bed and I know that I can sleep till the morning. (I)

It’s [CSA] not just meeting her needs, it’s meeting the needs of the family. (I)

We’ve seen a noticeable change in his behaviour. So much so that home life for everyone, myself, my wife and the other two children, has improved dramatically. (F)

Changes at home? – Oh ya! (F)

Still not often we go out as a family, but definitely more than we used to. (I)

It is apparent that parents appreciated the programme at CSA because of the perceived effects on their child. One parent gave the following statement and others voiced similar reactions:

When we arrived at the [previous] school he would just start to cry. And that conveyed to me that he was unhappy to go in there. We come to Camphill now, he jumps out of the car, and he runs up the path to kindergarten, he runs and he’s delighted – you can tell he’s happy to be there. He’s also a happier child at home. Everybody has said that he’s a happier child in general. Smiley, laughing child. (I)

Parents commented on significant positive changes in family life as a consequence, often related to reduction in parental stress:

I was stressed. But I was! I definitely was. But when you’re living in it, I don’t think you realise that. (I)

Part of the reduction in stress and feeling of relief which parents expressed appeared linked to the fact that their child was happier:

Because she’s happier, it’s nicer to be around her. One could have a bit of fun, which we couldn’t do before. (I)

The impact is on the whole family:

Before Camphill we were under a lot of stress the whole time, it was so difficult for other people to understand [him], whereas in Camphill they do understand [him] and his needs. (F)

There were other aspects of life where family life was perceived as improved or stabilised. For example, work life became stabilised, educational opportunities and studying opportunities improved, amount of time parents could give to siblings increased and activities as a family outside the home increased:

What difference has it made, is that I do what other people do now. I eat meals, I go for walks, I go out, I go to the – Oh I can go shopping! I can go shopping when I feel like it! (I)

Some families considered that CSA had saved them from breakdown and had enabled them to find a meaningful way of functioning while still remaining involved in their child’s life:

It’s (CSA) aided his brother’s life but it has helped us to run as a couple and it has helped us survive – to have what we feel is meaning in our life and it also has allowed us to feel we can contribute to our son’s care as well. (I)

[Previously] the family were in a great pressure regarding the care he requires and also trying to cope with everyday pressures and work and life in general. (I)
Everything suffers because you haven’t got time for yourselves, any quality time because everything centres on time for the child. (I)

There was less restriction on activities and on parent time with siblings as previously:

[Sibling’s] friends have grown up knowing that they have to be out of the house by 9 o’clock because they don’t want to disturb [child with special needs] in case there’s problems getting him off to sleep. (I)

Now, siblings were able to develop their education and social life more normally:

He [sibling] really has been able to develop more of an ordinary social life, more of an ordinary life of a 16-year-old with [his brother] being here [Camphill]. (I)

I think the boys [siblings] are certainly a lot more relaxed. (I)

We can all interact a lot more with him, without him diving off the deep end. And the consequences – improved 10-fold. (I)

Furthermore, the child with the disability was viewed as more happy:

. . . he’s been happy. . . And that rebounds on the rest of the family, because if he’s happy then we feel happy as well. (I)

The impact on education and careers was clearly noted:

Brother has been taking his diploma at college so from the study point of view everything has been calmer – work life more stable and no longer disrupted by calls to pick up the child. (I)

(Previously) there was just no way you could have studied or improved your career prospects or anything, just impossible. (I)

I’ve never been able to work because of [daughter with special needs needing care]; I’ve never worked since having her. (I)

Improvement in physical health and emotional well-being are apparent with reduced guilt and a reduced sense of failure. As one parent said:

It’s like a light at the end of a tunnel. (F)

The fact that the child may go away on a group home basis and return for weekends and holidays still brings challenges and some parents find it very difficult to have the child away from home. Yet, as one family put it:

From being apprehensive about having him as a very young child staying away overnight we now are absolutely convinced that it [being residential at CSA] is in [his] best interests as well as the family’s.

Discussion

The results underline the depth of concern from parents about life when their child was living at home before attending CSA on a residential basis. The classification of parent comments in the figures above indicate the degree of challenge presented by the child with a disability and these are consistent with the description of the children prior to admission. The results also are consistent with other studies which involved children with major challenges (R.I. Brown et al. 2006; Werner et al. 2009). Thus, the results relating to pre-admission behaviour of the children with disabilities in the home provide a graphic picture of the challenges faced by members of the family.

The results once the child attended CSA indicate considerable and positive change, not just for the child but for the family as a whole. It is important to remember that although children were as a rule in residence at CSA, contact with the family was maintained. They returned home on a flexible basis as describe earlier.

Family life showed interesting changes. Parents said they were able to enjoy time with their child and concerns appeared to be reduced while, generally, there were improved family relationships. Some families considered CSA had saved them from breakdown, and had enabled them to find a meaningful way of functioning while still remaining involved in their child’s life. The development of greater stability in the family was also noted. There was a sense that family life was less restricted while the child was at CSA, allowing the family to function more effectively. Although there were still challenges for some families, such as some restriction of family outings when the child was at home, these
families still considered that their lives had totally changed and in a positive way.

Generally, parents felt relief as a result of their child attending CSA. There was an overall reduction in stress levels and parents felt more relaxed with fewer worries and less guilt. There were other aspects of family life which were perceived as improved or stabilised, for example, work life, educational opportunities and studying opportunities, and increased time parents could give to siblings. Family opportunities outside the home increased.

The positive changes were for everyone in the family. In a number of cases, the parents mentioned that family and parental relations were improved. Parents felt more confident, and changes helped to avert the breakdown of the family.

The interplay between child improvement and the effects on family dynamics is seen as a major impact. Such results are consistent with the concerns underscored by Rillotta et al. (2010), who noted major negative effects of disability on other family members when the child is in the home without adequate supports. These authors also stressed the relevance of behavioural challenges, and their impact on many aspects of family relations.

Parents were invited to say what they thought might be happening in the future. Some of the comments were about themselves and their family, others related more to CSA as a service. In contrast to their previous feelings of desperation, many parents were now able to express a more positive outlook, with hope for the future for themselves, their family and their child with special needs. Some parents expressed a dramatic shift in their aspirations for their child. A significant factor in this was a sense of meaning and purpose in their child’s life, which they considered had been engendered through CSA. Some parents noted their recognition and acceptance that their child would never be truly part of a wider society. Despite this, their worries were alleviated and they seemed able to maintain a positive outlook for their child’s future because they believed there is a continuum of service available.

Parents noted an overall improvement in their family life. They could engage in activities with other children in the family with fewer restrictions. Families appear to feel less stressed and as a result they can probably function more effectively. This seems partly due to their child no longer being within the family home all the time, allowing more normal family activities and function to be restored, but it is also probably influenced by positive changes in the child’s behaviours. These changes also allow a more positive experience of the child within the family when they are at home – each evening, weekend or holiday time, depending on the situation. Family relationships improved for parent and siblings, work life is no longer interrupted and parents begin to express hopes for the future, for themselves and for their child.

Families perceived the services provided were important for the realisation of their hopes for a good quality of life for their child and their family, both in the present and in the future. This is an aspect which still receives low satisfaction ratings in terms of service delivery in several quality of life studies (e.g. see Brown et al. 2003), and appears to relate to lack of support for the family. Family quality of life is rated as one of the most important aspects of family satisfaction (Brown 2010). In the present study, this appears to have become severely damaged in many of the families prior to relief, but greatly improved after placing their child in a group home at CSA campus. Parent statements indicate that the support provided through CSA helped to re-establish a more stable and normal family life.

Families previously separated from neighbours, and restricted in terms of outings and normal activities, faced an excluded existence in their home and neighbourhood. With respite through CSA, the exclusion experienced by family members appeared to be reduced, and this normalisation seemed to be maintained once the child started to spend more time at home. The issue therefore is not just that of child treatment and support, but of ensuring families can cope and experience a more typical way of life relevant to all family members.

These challenges are not unique but reported by parents from several countries who are concerned with lack of family support from both services and the community (Brown 2010; Brown et al. 2010). It is this issue that needs to be addressed in further studies, in terms of policy and practice.

The result of this and other studies referred to above raise important policy issues. In cases where there is a child with very severe and multiple developmental disabilities, including extreme behavioural challenges which disrupt family life, the question
arises – should the child remain in the home? If so, what sort of supports should be provided for the family? They need to be the types that support parents and other members of the family in ways that overcome the losses that jeopardise effective family functions. This requires not just dealing with the child’s needs but effective analysis of the family situation, the resources required, and an evaluation of the effects that result from family support. But would that be sufficient in the types of situations described? There is a clear indication that families in such situations become isolated in the community, sometimes affecting the social life of siblings and reducing opportunities in terms of education and employment choices. This effectively becomes social exclusion for the family as well as for the child with a disability. This was not the intention of the inclusion movement but it is a reality for some families. Furthermore, it would appear that a reasonable argument could be made for the benefit of both family and the child with a disability for the child to be away from the family home for at least a period of time. Camphill, with its philosophy of anthroposophy and inclusive practices, is one example of this and its impact could be the focus of further studies (see Brown 2011 regarding comments on the CAS programme, and also Jackson 2011). This is not an argument for institutionalisation but a question of providing environments through which child and family can be stabilised and helped to integrate their lives on a more normalised basis. Such concerns raise serious questions about inclusion and exclusion, and the need for specialised treatment and education which, on occasion, may require the removal of the child for a period of time away from the home, although with increased parental involvement as child and family stabilise. The challenges outlined above require serious consideration through a clear examination of the evidence, the needs of children and families, and the alternatives that are required to effectively deal with this apparently growing concern.

Limitations

Due to time limitations, relating to the original purpose of the study, a retrospective investigation of how parents perceived the past and concurrently the present seemed most appropriate. However, the retrospective nature of a portion of the study should be kept in mind. It is recognised that the study was primarily directed to the potential effects of major changes to the facilities with the planning of a major roadway close to CSA group homes and other facilities. Nevertheless, the first author’s observations at the facilities plus the reactions of parents and personnel leave little doubt that parents perceived major changes and expressed dynamic effects on their family members as well as the child with challenging behaviours, through a process represented by care and support of children while the family received respite and time for renewal and adjustment.

Summary

The results are consistent with a number of other studies reported on the quality of life in families where a child with disability and major behavioural disturbance is present. In particular, there are issues of long-term stress with disruption of normal patterns of behaviour within the family. Policy and practice frequently focus on the child with a disability and less attention is given to parents and siblings. The impact, where there is a high degree of disturbance, appears to be associated with breakdown of the family and, noticeably, connections with the outside community of neighbours and normal community activities. It seems likely that such a cycle defeats the aims of social inclusion resulting in isolation for all family members.

The child with a disability and challenging behaviours as detailed in this study requires much greater support from services and community if they are to survive and enjoy a good quality of life. Periods of residential respite may be necessary when other resources are unavailable or do not meet the needs of the child and family. Early family intervention and support are also necessary and required to be at a level that deals with family needs for appropriate family relations. In the present study, day and residential care were associated with increased family adaptation and improved quality of life. These aspects require further investigation.

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