



A Valued Resource?

Understanding the quality of life of children and their families who access Camphill School Aberdeen, with reference to the proposed Aberdeen Western Peripheral Route

CONSULTANT'S REPORT

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This work was commissioned and funded by the Camphill Research Group. It was carried out by an independent consultant, Roy I. Brown (BSc, Dip. Psych, PhD, FBPS, FCPA, FIASSID), Professor Emeritus, Flinders University, Australia and University of Calgary, Canada; adjunct Professor Simon Fraser University and University of Victoria, Canada.

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Since this report was first published the Camphill Rudolf Steiner Schools (CRSS) have changed their public name to Camphill School Aberdeen.

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EXECUTIVE SUMMARY

1. Key Points

- **The children attending Camphill Rudolf Steiner Schools (CRSS) are multiply disabled and constitute one of the most vulnerable groups in the child population.**
- **Many have experienced repeated failure in other educational settings prior to admission.**
- **The presence in the home of children with severe behavioural disturbances poses acute problems for parents and siblings.**
- **Once admitted to CRSS, parents note positive changes in their child's behaviour.**
- **Admission of the child to CRSS also provides much needed time for the re-stabilisation of the family unit.**
- **A key and unique feature of CRSS is the provision of a quiet and peaceful environment. This is of critical importance given the children's particular vulnerability to ambient stimulation.**
- **Changes in levels of stimulation, such as those resulting from construction and operation of the proposed AWPR, even if attempts at mitigation are made, are very likely to impact seriously on many of the children since the current environment constitutes part of the therapeutic process.**
- **The consequences would have far reaching and damaging effects not only for the child but also the family unit.**

2. Overview

This report follows an initial document (Brown 2005) which examined the possible effects of the construction and operation of the proposed Murtle route for the Aberdeen Western Peripheral Route (AWPR) on the Camphill Communities, Aberdeen. The proposed road would overrun the entrance of Camphill Rudolf Steiner Schools (CRSS) Murtle campus and pass 100 metres from its residences (see Map 1, Appendix 3). This report focuses on children attending CRSS and their families.

The report provides an in-depth examination of the situation facing the children attending CRSS, both as day and residential pupils, and the potential effects on their families. There is an examination of the possible environmental effects on children, particularly those with multiple disabilities, and the likely impact on services offered by the School. This takes into account the underlying mission, philosophy and values of Camphill and the impact that the services provided by the School have had on the children and their families. If the integrated programme of CRSS, which includes the quality of the environment, is effective, then any major or long term changes to the immediate surrounding environment would pose major concerns in terms of programme viability.

Change of route

In December 2005, shortly after the reported study was concluded, the Scottish Executive abandoned the proposed Murtle option for the AWPR between the Camphill Communities at Newton Dee and Murtle Estates, both in Bieldside, Aberdeen, and announced a new route, the Milltimber Brae/Netherley Route (see Map 2, Appendix 3).

The report remains germane to the new situation, for it describes the quality of life of families and also their children with learning disabilities and other complex needs who attend CRSS, either on a residential or daytime basis, and participate in the care/education/therapeutic programme. As was the case for the Murtle option of the AWPR, the main concerns are that construction and operation of the AWPR (Milltimber Brae route) will have significant adverse impacts on the special needs children on Camphill Estate and on the work of CRSS.

3. Approach and Method

The evaluation approach was multi-faceted, involving informal observation, interviews, focus groups and information from health records.

Informal observation

The consultant carried out informal observation during 2 two-week stays on Murtle Estate campus and a number of other shorter visits, including further observations in other local Camphill facilities.

Interviews and focus groups

A series of individual interviews and focus groups were conducted with samples of parents who had children attending CRSS and with a number of personnel. An analysis of these discussions is reported, and provided in both histogram form (1:1 interview data only) and in a series of relevant quotations from original sources (both interview and focus group data).

Sample size

Twenty-three families of children attending CRSS were represented overall, in interview and focus groups. Twelve represented children from Murtle Estate and eleven were from Camphill Estate. During the period of study the number of children attending CRSS averaged around 82. There were 22 day pupils (3 of these are Amber Kindergarten) and 60 were residential. Twenty of the residential pupils were weekly boarders, and 40 'full residential' in term time. Therefore, the sample represented over a quarter of the children's families.

Sources and types of data

Consideration was given to the diagnostic, health and behavioural challenges facing the children as described in, and abstracted from, the health reports. Evaluation of the needs and vulnerabilities of the children as perceived by their parents and CRSS personnel was also undertaken. This process also included an examination of the changes in children prior to attending CRSS compared with their current status. This relates to performance and behaviour seen by the parents and by personnel. The report also looked at changes to family life over the same period, as viewed by parents.

Each of these aspects was carried out separately. One aim was to check whether there was a high level of reliability and concordance and, if there were variations, to note what these were along with their possible causes. While a longitudinal study would have been ideal, given the time available a study of a cross sectional nature with retrospective components was employed to assess before and after effects associated with the CRSS interventions.

4. Results and Discussion

There was a very high level of concordance between the different sources of information and different methods of obtaining data, which suggests high reliability and validity.

Profiles of the children

The information from health and behavioural records, in conjunction with the consultant's observations, and parental and personnel commentaries, raised a number of important issues which need to be taken into account.

First, the children attending the CRSS are not just children with learning disabilities, but children who are multiply disabled and have a wide range of recognised conditions, such as autism spectrum disorder. The literature has documented that such children frequently show aberrant and very disturbing behaviours.

Second, the records indicate that the children at CRSS are drawn from the extreme and most disturbed end of the behavioural spectrum. Such behaviours are frequently observed in the CRSS population. While a predominant number of children have autism spectrum disorders, there are other children with multiple diagnoses also involving extreme behaviour disturbances. It can be concluded that the children at CRSS are extremely disabled, particularly in emotional and behavioural terms (Figures 1-5 & 9).

The observations and perceptions of parents and personnel are in agreement with one another and also consistent with the literature, which describes the extreme conditions within this spectrum of disabilities. Most children are admitted to CRSS as a last resort because they cannot be managed in other environments, including home, school and community.

Impact on families

The commentary of parents, both individually and in the focus groups, demonstrates the extremely difficult and exceptional conditions under which families have lived on a day-to-day basis as a result of their child's disabilities and behaviour. Such children need not only care and support but also effective approaches to deal with their behaviour. At home the only persons available most of the time are parents and siblings (Figure 6).

Parents also noted that the behaviour of their children frequently affected relations with neighbours and the wider community. Testimony from parents pointed to the failure of other schools to meet their children's needs. Parents were sometimes asked to remove their child permanently or were frequently called to take their child away on particular days, because of behavioural outbursts.

Behaviour of the children

Details of the children's behaviour are summarised within the report. This includes such items as faeces smearing, screaming, running away, damaging property and sometimes, direct violence to individuals within the family or at school. Although not all the children showed all of these behaviours, the results clearly indicate that all children showed a range of multiple aberrant and extreme behaviours.

Stabilisation of behaviour

There is also clear evidence from both the parents' and the personnel's points of view that children's behaviour stabilised considerably following placement at CRSS, both while in the School and also when in the parental home. The reasons for this improvement appear diverse. A separate formal evaluation of the school's function noted the high level and diverse nature of the care and support that was on offer. This requires extensive knowledge of a child's behaviour and health conditions, and the availability of particular environmental resources. Personnel need great patience and understanding as well as professional resourcefulness (Figures 7 & 8).

Environment and approach of Camphill School

The integrated programme of CRSS, with its approach based on Rudolf Steiner methodology, is provided within an environment of peace and quiet. These

environmental characteristics are critical for children who are particularly vulnerable to changes in ambient stimulation and the high levels of stimulation that often occur in a normal environment, and which would be exacerbated by the construction and operation of a major roadway nearby. In other words, Camphill has both devised and protected an environment that is particularly conducive to maintaining a balance in children's behaviour (Figure 10). This is aided by personnel who, with a very high level of competence and dedication, provide care and intervention. To provide the necessary level of support to the individual child, there is also a high staffing ratio.

Positive changes in behaviour

Parents also frequently reported major changes in their children after a period at CRSS. In all cases that the consultant assessed the changes were positive and, although varied in extent, were, in most cases, very considerable. The possible causes for these changes are complex. Removal of the child from the family home enabled parents and siblings to re-stabilise and establish themselves as a normal family group. The parents felt they could now deal more effectively with their other children, even when the child with a disability returned for weekends or holidays. It was also noted that the children tended to be calmer and less challenging.

The views expressed are consistent with those found in the literature on autism spectrum disorder and other disabilities. It needs to be recognised that these children and their families are extremely vulnerable, and that the element of stability that has occurred is susceptible to changes in the environment. In other words, these children have to be handled with extreme care. Changes to their environment, sometimes even of a minor nature, are likely to cause regression, which may take considerable time to reverse.

Maintaining an integrated approach

It is very understandable that Camphill wishes to preserve its integrated approach, which includes its way of life, for the sake of its pupils and their families. It is also clear that parents do not wish any changes to the current situation which may result in disturbance of the delicate balance that has been achieved in securing a sense of individual and family stability. It would appear from the information collected that local authorities and external professionals have not always understood the nature or the impact of extreme

aberrant child behaviour on families and the extent to which the kind of specialised environments provided by CRSS are necessary for such children over a reasonably long period of time.

Preserving the CRSS integrated approach is of critical importance, because it has been successful in dealing with a population of children who have extreme needs. Such places of refuge, intervention and support are hard come by. Yet the kinds of children admitted to CRSS are increasing in the Western world. This is due to a variety of possible causes, amongst which are ambient levels of environmental pollution resulting from noise, traffic exhaust and population density.

Inclusion

The findings of this study certainly do not suggest that CRSS is a stagnant organisation. On the contrary, the School incorporates the better aspects of inclusion, wherever it can, enabling children, as they improve, to enter and sample the local environment through contact with members of the public in different social and educational settings and facilitating access by the local community to CRSS.

A valued resource

The residential model offered by CRSS, built around family-type living situations, plays an integral part in its programme. It permits high levels of individual support, combined with careful supervision and monitoring for each child. There are a variety of structures aimed at keeping staff stress levels at a minimum. Overall there is a much higher level of support than would normally be found in community services. This undoubtedly contributes to the overall effectiveness to the CRSS programme. While it was not within the scope and remit of this study to debate the detailed effects of particular aspects of the CRSS programme, it nevertheless must be pointed out that the results are consistent with the literature on extreme behaviour disturbance and multiple diagnoses, including autism spectrum disorder. The vulnerabilities of these children and their families are well known and documented. CRSS represents not only an important resource for Scotland, and the northeast in particular, at the present time, but will be required for increasing numbers of children and adults who have disabilities of this type.

5. Recommendations

Specific recommendations relating to child behaviour, families and the CRSS environment are detailed in the full report. They are based on the evidence that is available both from this study, plus the research and clinical literature. The overriding recommendation is that the Scottish Government and local authorities should do all that they can to preserve the nature of CRSS, support its programmes and help to provide a greater understanding of the work CRSS is carrying out and the effect it is having not just on the children, but also on their stressed and vulnerable families.

Three major recommendations are put forward:

1. It is extremely important that the Scottish Government and local councils as well as disability, social work, health and educational services recognise that CRSS is an exceptional resource, which should be supported, protected and advocated as a place where children with complex and multiple needs, including learning disabilities, who show extremely challenging behaviour, can gain support and assistance.
2. It is also critical to recognise that these services provide respite for families which enable many of them to re-stabilise and become functional again. This is in the interests of both the children and their families. It is in the interests of the government, as well as the range of services, that these positive effects on children and families can occur without disruption.
3. Lastly, the evidence indicates that the children attending CRSS represent an extreme sample of people with disabilities who are extremely sensitive to change and disruption, and the types of environment that precipitate or help to maintain aberrant behaviours should be avoided. The risks of developing the AWPR as proposed, or in any similar close proximity, should be avoided as the risks to children and families are extremely high given the nature of the children's disabilities and needs.

1. BACKGROUND AND CONTEXT

1.1 Introduction and background

This report describes a study, commissioned by the Camphill communities, to evaluate the potential impact of the Murtle option (see Map1, Appendix 3) for the Aberdeen Western Peripheral Route (AWPR) on the quality of life of children attending Camphill Rudolf Steiner Schools (CRSS) and on that of their families. It develops and expands the preliminary examination and this final report should be read in conjunction with the initial report (Brown 2005). In that report there is a summary of the international Camphill Movement, relevant details of the Camphill Communities sites and services along with a general description of the client population. It also describes the initial concerns in terms of the likely effects of the proposed Murtle option of the AWPR on the Camphill communities including CRSS and its pupils with complex and multiple additional support needs, including learning disabilities.

The Brown report (2005) includes a number of strong recommendations indicating that further investigations are required to adequately assess the impact of the AWPR on the Camphill communities. It further outlines key points to be taken into account when interpreting any investigation of impact. These are relevant for the interpretation of the current study and are summarised below:

1. CRSS represents a valued and unique strand of service delivery, for children with additional support needs.
2. CRSS practices and programme, based on a long-standing value system, are gaining recognition as key contributors to quality of life for individuals with additional support needs.
3. The AWPR is likely to compromise some of these values and practices.
4. The CRSS holistic approach to quality of life extends to the environment and nutritional aspects.
5. Location of AWPR raises significant issues around landscape & visual impacts and light and noise pollution.
6. Inadvisability of reducing an established and progressive provision for children with complex and multiple support needs, including ASD, when current and future demands are increasing in Scotland.

1.2 Change of Route

In December 2005, shortly after the present study was concluded, the Scottish Executive abandoned the proposed Murtle option for the AWPR between the Camphill Communities at Newton Dee and Murtle Estates, both in Bieldside, Aberdeen, and announced a new route, the Milltimber Brae/Netherley Route (see Map 2, Appendix 4). This route is currently being examined by Camphill for its potential impact on the Camphill communities, specifically CRSS Camphill Estate campus. As was the case for the Murtle option, it is recognised by Camphill that adequate and appropriate assessment of impact and detailed proposals for mitigation should take into account the particular sensitivities of the special needs children on Camphill Estate and the specific programme of CRSS.

This report remains germane to the new situation, for it describes the quality of life of families and also their children with learning disabilities and other complex needs who attend CRSS, either on a residential or daytime basis, and participate in the care/education/therapeutic programme. As was the case for the Murtle option of the AWPR, the main concerns remain that construction and operation of the AWPR (Milltimber Brae option) will have significant adverse impacts on the special needs children on Camphill Estate and on the work of CRSS. An additional concern is that some children from Camphill Estate, who are likely to be disrupted by the proposed AWPR, attend school on Murtle campus. If such disturbance occurs, these children are likely to disrupt children on Murtle campus who also attend the school, with a potential negative spiral effect. The impact will also be on personnel and families. This report highlights the vulnerability of the children attending CRSS and deems it essential to protect their living and learning environment as far as possible, to ensure continuation of their current quality of life and that of their families.

1.3 Context: Quality of Life

1.3.1 Introduction

Quality of life is a modern and key concept, which is now receiving the attention of the United Nations, the European Economic Community and many other bodies. Those working in this field (e.g. Schalock et al 2002) are concerned that, as society develops

and changes, and as services for people with learning disabilities¹ aim to provide more sophisticated services, consideration of individual and family well-being and quality of life become crucial. Quality of life conceptualisation has, therefore, been expanded to include family quality of life (see Turnbull et al 2003). It will be seen that this concept is fundamental to understanding the needs of children and families who use the services of Camphill.

1.3.2 Modern principles of quality of life in relation to learning disabilities

It may be helpful to outline some concepts and principles of quality of life so as to demonstrate the areas in which CRSS seeks to enhance quality of life and the way in which the AWPR proposal may challenge and limit these concepts and principles. Quality of life is an evolving concept which has as its guiding principle that all humans are entitled to enjoy quality lives. The range² of definitions and description of quality of life give some indication of the breadth and depth of the concept (Table 1).

¹ UK terminology. 'Intellectual disabilities' is the International terminology

² Adapted with permission from Brown, I & Brown, R.I. (2003) Quality of Life and Disability: pp 102-106.

Table 1 Definition /Description	Source
The social well-being enjoyed by people, communities and their society.	Bach, M. and Rioux, M. (1996)
Is both objective and subjective, involving material well-being, health, productivity, intimacy, safety, community and emotional well-being.	Cummins, R (1997)
A multidimensional concept involving personal well-being. Is concerned with intimate relationships, family life, friendships, standard of living, work, neighbourhood, city or town of residence, the state of the nation, housing, education, health and self.	Felce, D. and Perry, J. (1997)
Is experienced when a person's basic needs are met and when he or she has the opportunity to pursue and achieve goals in major life settings.	Goode, D. (1988)
When an individual, with or without disabilities, is able to meet important needs in major life settings (work, school, home, community) while also satisfying the normative expectations that others hold for him or her in those settings, he or she is more likely to experience a high quality of life.	Goode, D. (1990)
An emphasis on promoting general feelings or perceptions of well-being, opportunities to fulfil potential and feelings of positive social involvement	Goode, D. (1997)
The discrepancy between a person's unmet needs and desires. Referring to the subjective or perceived as well as objective assessment. Relates to all life domains. Recognizes interaction between individual and environment.	MacFarlane, C., Brown, R.I. and Bayer, M. (1989)
Represents the degree to which an individual has met his or her needs to create their own meanings so that they can establish and sustain a viable self in the social world.	Parmenter, T. (1988)
The degree to which an individual enjoys the important possibilities of his or her life.	Renwick, R. and Brown, I. (1996) and Rootman et al. (1992)
Person's desired condition of living (primarily related to home and community living, school or work, health and wellness).	Schalock, R. (1997)
A useful sensitizing concept that focuses research on the broader life-defining issues by attempting to comprehend the perspectives of the person with a disability.	Taylor, S. (1994)

From these definitions/descriptions emerge a number of quality of life goals, ways to reach those goals and ideas on the way quality of life functions.

Quality of life goals

- achieving physical, emotional and material well-being
- being satisfied with life
- developing positive self-concepts
- enhancing personal meaning
- enhancing various areas (domains) of life
- enjoying life
- improving social and environmental conditions
- meeting needs.

Ways to reach quality of life goals

- perceiving needs
- recognising individuals' feelings about the good things of life
- recognising ways a person wants to live
- responding to what is important to individuals
- ensuring opportunities are available
- improving social inclusion and social involvement.

Quality of life functions as

- a sensitising concept
- an interaction between the individual and his or her environment
- a complex of objective and subjective measures
- the discrepancy between what one has and what one would like.

Quality of life as it relates to the individual is a holistic concept and as such is concerned with the whole of an individual's life and the context in which that is lived out. This has led to the identification of some areas (domains) which are relevant when looking at quality of life (Table 2).

Table 2: Some suggested domains of quality of life		
About the individual	About what the individual does	About the environment
<ul style="list-style-type: none"> • Material well-being • Physical health • Psychological well-being • Spiritual well-being • Social well-being • Self-image • Self-determination 	<ul style="list-style-type: none"> • Work • Leisure activities • Personal development • Interpersonal relations • Intimacy • Education 	<ul style="list-style-type: none"> • Social inclusion • Rights • Safety • Societal well-being • Home life/housing • Community resources

To this list Mitchell and Winslade (1990) and others add 'Political Climate'.

Although quality of life may at times focus on particular aspects on an individual's life it is recognised that all domains are interrelated and interactive. 'Quality of life is about having a life that is rich and meaningful to each individual' (Brown & Brown 2003, p.25).

1.3.3 Relevance of quality of life to Camphill and AWPR proposal

Quality of life is fundamental to understanding the needs of children and families who use the services of CRSS. It is a concept which is not inconsistent with the philosophy and values of CRSS (Brown 2005). These can be summarised as follows:

- recognition of uniqueness of the individual
- respect for dignity and choices of the individual
- enabling the individual to realise their potential
- importance of addressing physical, psychological, emotional and spiritual aspects for well-being
- the role of social, cultural, artistic and educational activities in well-being
- the role of the environment in supporting the above

Further, the above definitions and principles of quality of life are to a considerable degree demonstrated through the practices of CRSS,³ key of which are:

- holistic and integrated approach encompassing care, education and therapeutic/medical activities

³ For a more detailed account see Jackson, R (2006) *Holistic Special Education: Camphill Principles and Practice*

- inclusion of pupils with a community based campus
- mutuality of learning relationships between personnel and the pupil and their parents
- supportive role of natural and built environment
- integration within the local and wider community

It is important to note that in families where there is a child with complex and multiple additional support needs the quality of life of all family members can be severely compromised. For example, it has been observed that when there is a child with autism who shows disturbed emotional behaviour, the lives of parents and other family members are particularly vulnerable (Brown et al 2006). However, as that article indicates, it may not be just the condition of autism which is relevant here, but rather the behaviour that is shown. Therefore, it is considered that not only those children with Autism Spectrum Disorder will cause families to be vulnerable but also those with other diagnoses who display challenging behaviour. Children who attend the CRSS do not all have autism spectrum disorder, but they all have a range of other greatly disturbing and challenging behaviours.

It is increasingly recognised in many countries as community inclusion has advanced, that there remain children whose needs are so complex that the support and intervention of specialised facilities are critically important to the child's and family's well being (eg as in the MukiBaum services, Toronto, Canada). Even within the missionary approach that has been taken to inclusion and community living, it has been recognised that, however important this type of inclusion is for the majority of persons with a disability, there are instances and times where removal from the family is critical to meet the needs of the child and the family with respect to support, intervention and treatment. Such action thus provides the best quality of life for both the child and his or her family. Children attend CRSS due to the fact that it has not been possible, in the vast majority of cases, to meet their needs either within the family home or within other mainstream or special education/training establishments, even with extensive support provision from social, educational and health services. In such cases it could be argued that in provisions such as CRSS, where the social pedagogic model operates and the concern is for the child as a whole and for their family, that greater and meaningful inclusion is

possible and an enhanced ability to meet the needs of the child and family than in mainstream settings (Jackson 2004, p.253).

From the foregoing it can be seen that quality of life of pupils, their families and personnel is an appropriate framework within which to evaluate the proposed proximity of the AWPR to CRSS. A further contextual orientation for the research study comes from reviews of the literature on:

- Sensory perception in ASD
- Effects of noise and pollution on health and well-being

Because these two areas are relevant to the potential impact of the AWPR on the pupils attending CRSS, prior to going onto the main research study, some necessary background from the literature is provided below in sections 1.4 and 1.5.

1.4 Sensory perception in autism spectrum disorder

It is relevant to include a review of the literature⁴ relating to sensory perception in individuals with autism spectrum disorder since:

- the initial study indicated that a high proportion of the children attending CRSS have ASD
- the proposed AWPR is likely to increase the level and type of sensory stimuli at CRSS.

1.4.1 Sources of Evidence

It should be noted that there are few, if any, experimental studies in terms of sensory measurement in relation to people with autism spectrum disorder. This arises in part from ethical concerns in subjecting individuals with emotional difficulties related to sensory stimulation to variations in sensory stimulation. Much of the evidence is from other types of research studies (e.g. observational studies, parent interviews and focus groups) plus clinical and allied reports.

⁴ Dr. Vicky Duffield undertook the survey of this literature on which this section of the report is based. The literature was researched using Web of Science, Medline, Psych Info and Eric databases. Key words used were autism/autism spectrum disorder; sensory integration; noise; sensory profile; hyperacusis; hypersensitivity; sensory motor therapies; environment.

1.4.2 Range of Sensory Disturbances

Reports support the fact that many individuals with autism have some form of sensory impairment (e.g. Talay-Ongan and Wood 2000). Many sensory modalities to which individuals with ASD are susceptible have been identified within the literature and these include sound, vision, touch, taste and smell. Some researchers have noted more evidence is required to clarify the range of sensory disturbances related to ASD and that the conclusions made may not be representative of the full range of autism spectrum disorders, (O'Neill and Jones 1997). These concerns have some validity but the fact remains that there are many reports of sensory disturbance amongst children and adults with autism spectrum disorder. Thus the empirical, if not experimental, evidence for sensory disturbances in ASD would appear to be strong. O'Neill and Jones (1997, p.284), in reference to personal accounts of autism, indicate that anomalies were in 'perception of sound, vision, touch, taste and smell as well as kinaesthetic and proprioceptive sensation'. They list the following:

- Hyper and hypo sensitivity to stimulation
- Sensory distortions
- Sensory tune-outs (i.e. sound or vision go blank)
- Sensory overload
- Difficulty processing information from more than one channel at a time
- Difficulty identifying the channel that stimulation is being received.

These personal accounts further suggest that sensory anomalies are portrayed as contributing to high levels of distress, fear and anxiety with consequent disrupting of daily life and social function (O'Neill and Jones 1997, p. 285). Grandin (1995) also reported that there are sensory challenges such as noise sensitivity and over sensitivity to touch, which influence learning, communication and are also reflected in social limitations. There are a number of books published by people with autism, such as Donna Williams⁵, which further describe the types of communication and social interaction challenges. Cesaroni and Garber (1991, p.305) describe problems with the experience of touch, which may be recognized as intense and overwhelming, as well as confusing. Carpenter (1992, p.292) reported adverse responses to light, 'My eyes are very sensitive to light and I squint as a result.'

⁵ <http://www.ont-autism.uoguelph.ca/books-by-ASD-authors.html>

Noise

In a similar vein Grandin (1990, p.13), a respected educator and researcher, who suffers from autism spectrum disorder reported, 'My auditory system is like an open microphone set at full blast. I can turn the mic on or off, but the volume cannot be adjusted'. Ward and Alar, (2000, p234) provide a personal account of a 20-year-old man with autism. The young man states:

'sudden loud noises are very stressful for me. Especially things like gunshots, loud motors and sirens. My mom took me through a drive-in car wash once when I was in grade school and I was terrified'.

It was also noted that over the years he has managed to train himself to tolerate some of these challenging noises, but that the possibility of unexpected loud noises is a constant source of low-level anxiety for him. In a treatment study of sounds effects (McCord, Iwata, Galensky, Ellingson, & Thomson 2001) the authors underscore the high level of disruption that can occur including self-injurious behaviour as a response to noise (e.g. phone ringing, fire alarm, people talking).

Again, at an anecdotal level, there are extensive records of a wide range of studies in terms of hypersensitivity to noise and developmental disability (McCord et al 2001). Parents of children with autism report high levels of abnormal sensory responses than parents of typically developing children. Baranek (2002) reviewed papers published in the 30 previous years in relation to sensory and motor intervention and autism. The review confirmed that individuals with autism showed sensory and motor difficulties in many cases at some point in their early development.

Hyperacusis

Turning to the issue of hyperacusis (abnormal loudness perception) and ASD, Khalfa, Bruneau, Rogé et al (2004) examined the perception of loudness in participants with autism and other neurotypical participants. The results support the view that individuals with autism have enhanced perception and reduced tolerance of loudness (p.91). Rosenhall, Sandstrom, Ahlsen & Gillberg (1999) indicated that almost 1 in 5 individuals with autism who have normal hearing also have hyperacusis. They examined 199 children and adolescents and carried out hearing testing for hyperacusis, which affected 18% of the autism group and no percent of the matched sample.

Auditory Hyperacuity

When considering the wider range of sensory sensitivities a number of studies indicate that these children perceive sensory information differently to typically developing peers (Talay-Ongan and Wood 2000). Particularly relevant in this study is the finding that auditory hyper-acuity is said to be dominant in autism, i.e. 'hearing the sounds of planes, trains, alarms or television before others can hear them' (p. 205). Some parents reported "faint" background noises impacted on their child (e.g. quiet music). Gomes, Rotta, Pedroso et al (2004), in a study to test auditory hypersensitivity in children and teenagers with autism spectrum disorder, found that 23.9% of their sample were clinically diagnosed as over-sensitive to sound.

1.4.4 Sensory problems central to ASD

Researchers and clinicians in the field of ASD have tried to describe the issues around evolving autism in some detail. Dawson and Watling (2000, p.415) noted that although sensory processing and motor abnormalities are neither universal nor specific toward autism, the prevalence of such abnormalities in autism is relatively high. Wing and Gould (1979) suggested that sensory anomalies represented one of the two primary symptoms of autism. In other words, sensory anomalies are not only common amongst the population in terms of clinical recognition and behaviour observation, but they also are central to the challenges faced by people with ASD. This is backed up by the work of Ornitz (1989) who suggests that there is a disturbance of sensory modulation and an over or under reactivity to sensory stimuli and that:

'disturbances of social relating, communication, language and the bizarre responses to the environment are consequences of a demodulation of sensory input' (p. 174).

Many of these statements arose from work carried on in relation to neuro-physiological studies of autism

1.4.5 Summary

The review suggests that there is strong evidence that individuals with autism have, as a group, disturbed sensory perceptions, with an inability to modulate incoming sensory information. There is dominance of hyper-sensitivity to sensory stimulation, although some have hypo-sensitivity. When hyper-responsive, a variety of extreme behaviours

may be observed which are highly disruptive to the individual's learning, social interactions and to the behaviour of those around them (see Frith 2003; Grandin 1992; Hill & Frith 2003; Wing 1993; Williams 1992). Although experimental studies are limited, the commentary from parents, therapists and other professionals, along with self-reporting by people with autism spectrum disorder, do indicate a range of abnormal perceptions, including sensitivity to sound, particularly loud and sudden sounds and an abnormal perception of loudness. Some studies have confirmed hyperacuity and hyperacusis by audiometric assessments and found them to be present much more frequently in individuals with ASD than in the general population. It is important to note that, abnormal responses to sensory stimuli are not specific to autism, and are characteristics of other learning disability disorders (James and Brown 1992; Humphries 2007; Nulman et al. 2007) found amongst the children attending CRSS.

1.5 Effects of noise and pollution on health and well-being

This section of the report is based on a review of the literature⁶ related to the effects of noise and air borne pollution on health and well-being.

1.5.1 Source of evidence

It should be noted at the outset that none of the following research studies examined the effects of noise and airborne pollution on individuals with learning disabilities or specific conditions such as ASD. However, the studies do illustrate some of the challenges involved for individuals who are susceptible to respiratory and allied diseases, including allergies. This is relevant to the present study in that individuals with learning disabilities, particularly autism, are susceptible to such conditions.

1.5.2 Noise and health

Haines, Brentnall, Stansfield et al (2003), state that their results from qualitative research consistently demonstrate that children are a high-risk group, vulnerable to adverse effects of noise exposure, especially in terms of performance, motivation and

⁶ Review carried out by Robert Melrose, MLIS, Librarian, Down syndrome Research Foundation, Burnaby, British Columbia, Canada, The search engines employed for this investigation were Campbell Collaboration, Psych Info, PAIS, Applied Science Index, Cambridge Scientific Abstracts, EBSCO Academic Search Premier and Pubmed

annoyance. Other studies on children exposed to different types of noise, showed larger effects for children exposed to high levels of noise compared to a low-noise exposure. The range of coping strategies that children employed to combat noise exposure in their lives was dependent upon the amount of control they had over the noise source. Road traffic noise has also been shown to negatively affect sleep patterns, even at low levels (Bluhm, Nordling & Berglind 2004). It also has the potential to induce stress reaction during sleep with consequences for conditions such as asthma, chronic bronchitis and neurodermatitis (Ising et al 2003).

1.5.3 Airborne pollutants and health

Kim, Smorodinsky, Lipsedd et al (2004), reported associations between respiratory symptoms and residential proximity to traffic. Studies showed, that an association between respiratory symptoms, including asthma, and traffic related pollutants were supported. A study by Finklestein, Murray, Jerrett et al (2004), on traffic air pollution, suggested subjects who have exposure to chronic air pollution (i.e. a residence within 50 metres of a major urban road or within 100 metres of a highway) were more likely to have a diagnosis of pulmonary disease, chronic ischemic heart disease or diabetes mellitus, and that these individuals had an increased risk of mortality. A carefully controlled study by Zmirou, Gauvin, Momas et al (2004), with 217 matched pairs of 4 to 14 year olds, suggests that road related pollutants might have contributed to asthma. A recent study published in *The Lancet* (Gauderman et al 2007) has indicated that living within 500 metres of a major road or motorway can damage the development of children's lungs, with potential long-term consequences for diseases such as asthma and bronchitis. Furthermore, the study indicates that the adverse effects of exposure to traffic on lung development occur at the local level and are independent of regional air quality.

1.5.4 Summary

The articles for the most part are from refereed journals, and have been reviewed by peers. They illustrate the growing concerns relating to traffic noise and pollution on health from a wide range of countries. The literature shows that noise and air borne pollutants can have a detrimental effect on the general population and that children can be more vulnerable than adults. The studies reported above, although not specifically with children with autism spectrum disorders or other complex needs, raise some

important concerns for CRSS. The section on sensory perception detailed earlier suggests the children with ASD often do not have psychological control in terms of a personal ability to moderate the impacts of noise. The reports of sensory overload are extremely common in the case of children with ASD. If noise from traffic and allied pollutants have negative effects on the health and well-being of children without abnormalities, it seems likely that children who have shown particular sensitivity to noise and sensory stimulation and are also prone to allergies/sensitivities and sleep disturbance are even more likely to be susceptible.

1.6 Relevance of literature reviews to assessment of AWPR and CRSS

It may be criticised that many of the studies relate to, or include, a wide range of anecdotal or non-experimental commentary. It should be pointed out that not only is there abundant evidence that personal perception influences behaviour outcomes (Andrews 1974; Andrews&Whitney 1976) but also that such reporting is correlated with the situations that the children face. Children attending CRSS, including those with ASD, show major disturbances in a variety of areas including sensitivity to sensory stimulation, challenges with information processing, sleep disturbances, allergies and respiratory problems. The review of the literature confirms the potential for negative impacts on health and well-being from noise, pollution and increased sensory stimulation. This has relevance for the assessment of the impact of proposed AWPR on CRSS.

Camphill professionals have highlighted the above concerns for many years and increasing evidence from the literature supports their concerns in this matter. Those living and working with the children at CRSS, teachers, carers, therapists and medical personnel, are aware of and deal with the issues of noise and pollution. Intensity, suddenness and unfamiliarity of sound, for example, interfere with therapy and can induce challenging behaviour. For these reasons the CRSS therapeutic lifestyle aims to foster low ambient noise and pollution levels, creating an environment without undue intrusive sensory stimulation. Allergies are carefully monitored and attention paid to diet with the growing of organic meats, fruits and vegetables. This approach has been central to the development of an holistic therapeutic lifestyle at CRSS for over 65 years. CRSS must examine any proposed changes to the surrounding environment carefully. They

are wise to take a cautious and careful approach to any impacts, which might lead to a disruption in the therapeutic and lifestyle approaches they employ.

2. RESEARCH STUDY: Methods and analysis

2.1 Introduction

One of the central activities to be carried out in any appraisal of CRSS relates to the impact of its 24 hour integrated care/education/therapy programme on the children in its care. In doing this it was important to have a clear grasp of the types of children and their families. It was also important to assess what changes had occurred both in the children and in the families as a result of their placement at CRSS and their inclusion in its integrated programme. Further, it was necessary to understand the philosophy and value system of CRSS which underpin the practice and integrated therapeutic approaches of the organisation. Details of these aspects of care are provided elsewhere (see Brown 2005; Jackson 2006).

Given the philosophy of CRSS and the development of a quality of life approach to learning disabilities it was appropriate to review the results of the study in these two contexts (i.e. Camphill philosophy and quality of life), with the addition of a family quality of life approach, accenting issues and concerns as registered by family members. To round out this approach it was also deemed necessary to assess whether the stated philosophy and approaches of personnel were consistent with the overriding ethos and intent of Camphill itself. In this way it seemed possible to provide an overarching view of the effects on the children and families and the impacts that the AWPR would be likely to have on the programme and services of CRSS.

2.2 Methods

2.2.1 Choice of study

Ideally, a prospective study would have been carried out, but in the time available a retrospective study of how parents perceived the past and, concurrently, the present, seemed most appropriate. How parents observed the present was seen as an important priority.

2.2.2 Selection of participants

The participants for individual interviews and focus groups were selected on a random basis. To achieve higher participant numbers others were then recruited based on

availability. All were given the choice of participating in an interview or focus group. It would probably be reasonable to regard this as a convenience sample. The same procedure was followed for parents and CRSS personnel.

2.2.3 Ethical issues

Ethical approval was gained through an ethics committee. Prospective study participants were supplied with basic information, which included the reasons for the collection of data, the nature of the interview or focus group, the observance of confidentiality (no names of adults or children to be used in the final report), the right of the participant to terminate any interview or focus group or to decline to answer any questions without impact on service delivery. Further, all tape recordings were labelled by code and kept separate from the list of names in a secure environment.

2.2.4 Procedure

The procedures employed for the study were affected by the conditions that were prevailing at the time of the consultancy, including time restrictions and the final resources that were available.

2.2.4.1 Informal observation

The researcher spent two separate full weeks, both day and night, on the Murtle Campus. Visits were made to observe children in nursery, school, around the campus pathways and recreational areas and in their group homes. Their interaction with personnel was also observed. Wherever possible, the researcher participated in activities, such as meals and group walks. Researcher interaction with children took place whenever a child indicated involvement was desired.

2.2.4.2 Interviews

Apart from these types of observation, the researcher set up interviews on an individual basis with parents/primary carers and CRSS personnel. These took place on Murtle campus or by telephone. Interviews lasted from 20 minutes to 1.5 hours.

- Parents/primary carers

Parents of children attending CRSS, both Murtle and Camphill campuses and the Amber kindergarten, located on Murtle campus, participated. Seventeen

parents were interviewed (10 mothers, 1 foster mother and 6 fathers). In some instances both the mother and father of a child participated.

In addition, two parents who had children without disabilities but attended the integrated nursery on the Murtle Campus participated. These parents were interviewed together, but separately from other parents. Their data is summarised in Appendix 1 but is not included in the main report. The characteristics of their children are not included in the data tables.

- Personnel

Nine members of CRSS professional personnel were interviewed including teachers, therapists, craft instructors, house coordinators

2.2.4.3 Focus groups

Focus groups were also held with parents and CRSS personnel.

- Parents

Seven parents of children attending CRSS, both Murtle and Camphill campuses, participated in 1 focus group. This represented 6 children and 5 families (2 sets of mothers and fathers were present. i.e. 7 parents in total). One family had 2 children with major disabilities attending CRSS.

- CRSS personnel

Six CRSS professional personnel including teachers, therapists, house coordinators took part in 3 focus groups, each with two members of CRSS personnel.

2.2.5 *Interview/focus group process*

In all individual interviews and focus groups were semi-structured, with the researcher being as non-leading as possible. It is recognised that all participants were aware of the proposal for the AWPR, and that this was the issue which had precipitated this research intervention. The topic guide covered broadly the following areas:

For parents/primary carers

- Background information on participant, their family and their child at CRSS
- Life prior to their child coming to CRSS and impact on participant and their family life
- Family life since child had been attending CRSS
- Any changes noted in child behaviour
- The particular aspects of CRSS which are important to the participant, their child and family.
- The potential impact of the AWPR on CRSS

The aim of the interviews and the parent focus group was to attempt, in a realistic way, to obtain details about family life before a child came to Camphill and during the time that the child was at Camphill (i.e.: current situations).

The researcher gave information along the following lines:

‘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. And then to lead on from that to ask you about what you think might be the potential impact of the new road. I think you’ve all looked and probably seen diagrams and maps of the relevant proposals.

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.’

Following this initial introduction some background information was sought about the individual being interviewed and also about the family and child. Issues such as age, whether the parents were employed, how long the daughter or son had been at Camphill and how she / he was at the time of the present recording were covered. This was followed by a series of questions about the behaviour of the child prior to attending CRSS and their current behaviour. The impact of their child on the family was also explored. Finally parents’ perceptions of the impact of the proposed Murtle option for the AWPR on CRSS was sought.

For personnel

- Background information of their position within CRSS
- The characteristics of children attending CRSS
- Any changes or otherwise in children after some time in CRSS
- The particular aspects of CRSS which are important to the participant, the pupils and their families
- The potential impact of the AWPR on CRSS

In all sessions the researcher requested whether the interviews could be tape-recorded. In one case this was declined and as a result, and with agreement, notes were made. Throughout, the researcher made notes at the same time as the tape recording.

2.2.6 Analysis

Data from the interviews and focus groups were analysed independently. The method of analysis constituted a mixed qualitative and quantitative approach. The researcher set out a framework for a qualitative analysis, but allowed for additional categories to be added by a qualified research assistant, so openness could be maintained in capitalising on content categories. It was possible to categorise statements and thus numerical frequency could be stated in the case of individual interviews. Dr Nancy Jokinen, a social worker, carried out the category analysis of the interviews and focus group content. This provided a level of independence to the study which was aimed at high reliability and validity. The information is presented in figure format along with quotes from transcripts.

Key themes from parent interviews and focus groups

- The diagnosis of the child with special needs
- Other conditions that the child had or has
- The families concerns regarding the child's behaviour, prior to CRSS
- The impact of the behaviours on the family
- Changes in the child during his or her period at CRSS
- Changes in family life since the child started CRSS

Other themes included:

- Future plans of parents/family
- The attributes of CRSS
- Parents' perception of CRSS personnel
- Perceptions of CRSS's relationship to the wider community
- Impact of the AWPR

Key themes from CRSS personnel interviews and focus groups

- Profiles/Characteristics of children attending CRSS
- Changes in children after period of time in CRSS
- Important aspects of CRSS as a therapeutic environment
- CRSS's relationship to the wider community
- Impact of the AWPR on CRSS

The statements recorded were grouped and categorised under the above themes. Main themes were expanded as the need arose and several sub-themes emerged from the data, (e.g. impact of behaviours on the families, sub-themes: impact on marriage, siblings). The presence of themes and sub-themes, along with their frequencies, were entered into an Excel file. Each entry was re-checked with the print copy of the transcript analysis. Written copies of each transcript and analysis were stored minus individual identification.

Focus groups

In the case of focus groups, frequency of an item was not noted as interaction discussion made it impossible to identify individual responses or deal with repetition in the discussion. In these instances presence or absence of a category was noted. Again, new categories were added as additional points emerged. The focus group not only increased sample representation but served as a validity check on information, individual interviews, and other sources

The principal researcher reviewed the data, and several questions were raised during this process as some information was not clear and the original tape had to be consulted again or notes provided the missing comments. In a few places missing data did occur, but the vast amount of information was clear and straightforward. As questions arose

about interpretation of particular headings, these were clarified and re-classification made where appropriate. The data were then used to provide histograms of the themes that emerged, and these are discussed essentially under the headings outlined above (i.e. by individual parent/carer or personnel and by focus groups).

Following analysis it became clear that the themes emerging in the interviews and focus groups were consistent and therefore to avoid undue repetition the focus group discussion, where possible, is integrated.

2.2.7 Sample context

During the period of the study the total number of pupils attending CRSS averaged around 82 pupils. There were 22 day pupils (3 of whom attended Amber Kindergarten) and 60 were residential. Twenty of the residential pupils were weekly boarders, and 40 'full residential' in term time ,i.e. there were no regular arrangements for going home, although some may have had visits home for special occasions at some point in the term.

Sample Interviewed

Twenty-three families of children attending CRSS (12 from Murtle campus and 11 from Camphill campus) were represented overall i.e. in the individual interviews plus the focus group. Thus just over a quarter of the children's families were interviewed. The children's average age was 12.7 years with a range of 6-19 years. Their period of attendance was 4.7 years, with a range of 1-13 years.

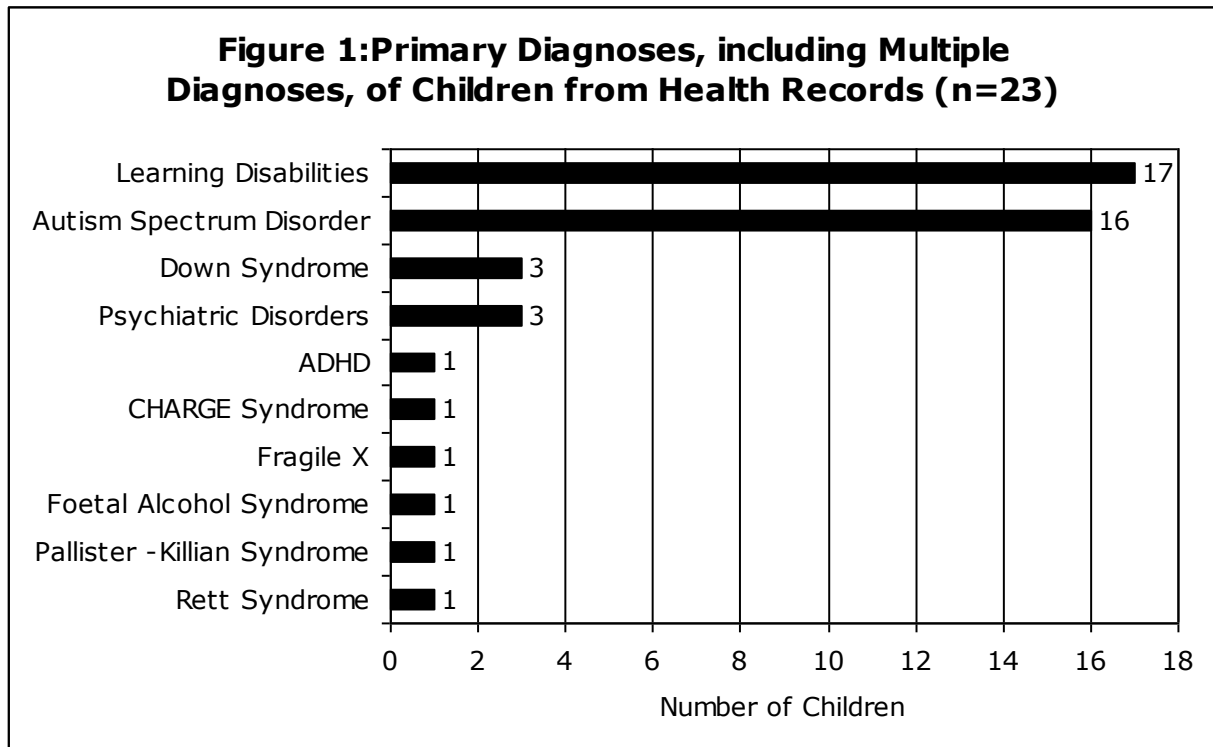
3. RESEARCH STUDY: Results

3.1 CRSS children's profile data

Information was provided by Dr Stefan Geider, medical officer of CRSS, and related to diagnosis and relevant allied information for the children whose parents participated in the interviews and focus group. The names of the children and families remained confidential. The diagnoses presented are those reached by NHS health and medical professionals. The data are presented in Figures 1-4. It should be noted that the data refer to incidence and therefore may total more than the number of children. Although the data refer only to the sample of children (n=23) whose parents took part in the study, Dr Geider has confirmed that the profiles/characteristics emerging would generally be applicable to the whole CRSS population, i.e. it appears representative.

3.1.1 Primary Diagnoses

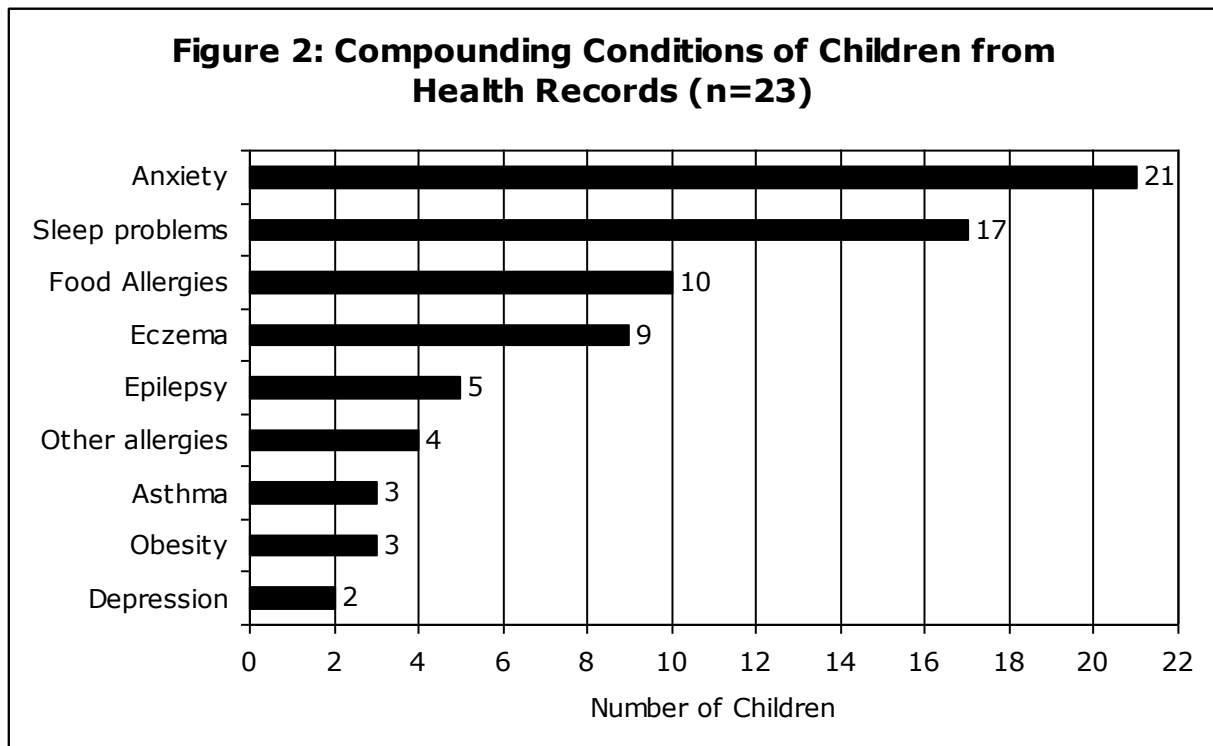
The primary diagnoses of the children are shown in Figure 1.



In the sample of 23 children, there are a substantial number (17 of the 23) diagnosed as having learning disabilities. Learning disability was the most common primary diagnosis amongst this sample. There were 16 children with Autism Spectrum Disorder (ASD), two of which 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 (Figure 1). These are all complex diagnoses which have physical, learning and emotional/social/behavioural consequences.

3.1.2 Compounding Conditions

These children also had a variety of compounding conditions to be taken into account, Figure 2.

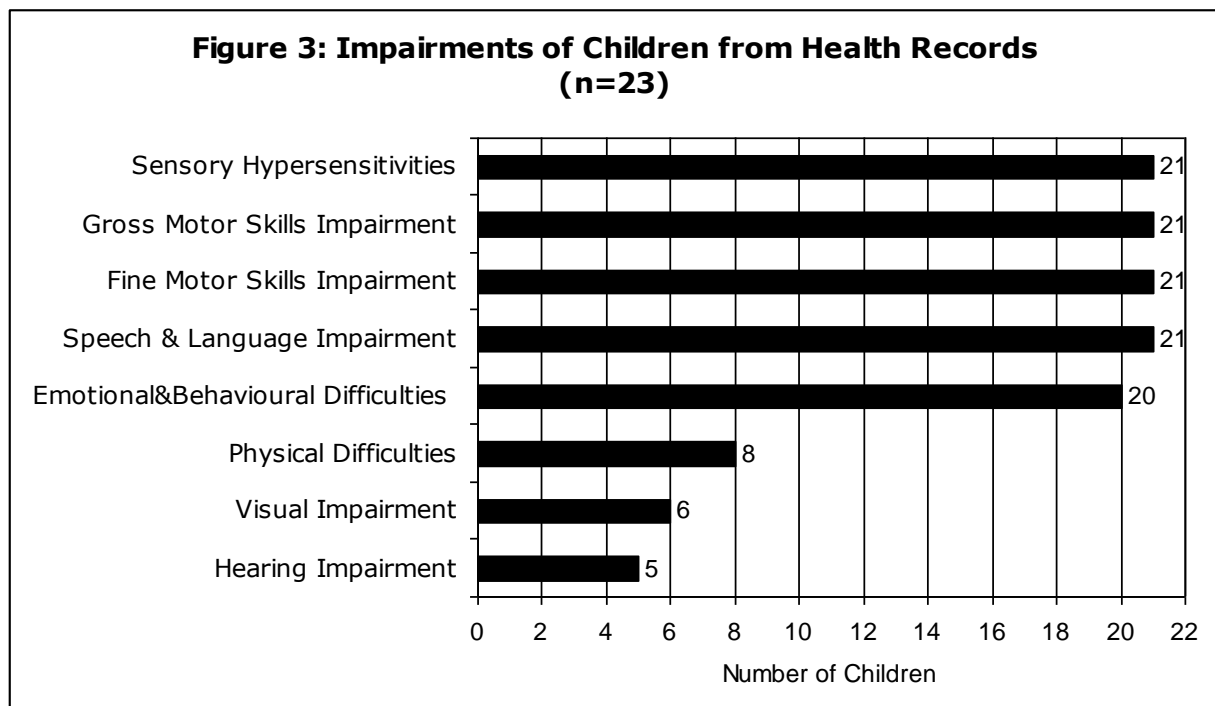


Anxiety was the most common compounding challenge, occurring in almost all the children (21 children) and two children had been diagnosed with depression. Sleep problems were common (seventeen children) and a significant number suffered from

allergies (4 children) of which ten were food related. Eczema, epilepsy, asthma and obesity were further compounding conditions.

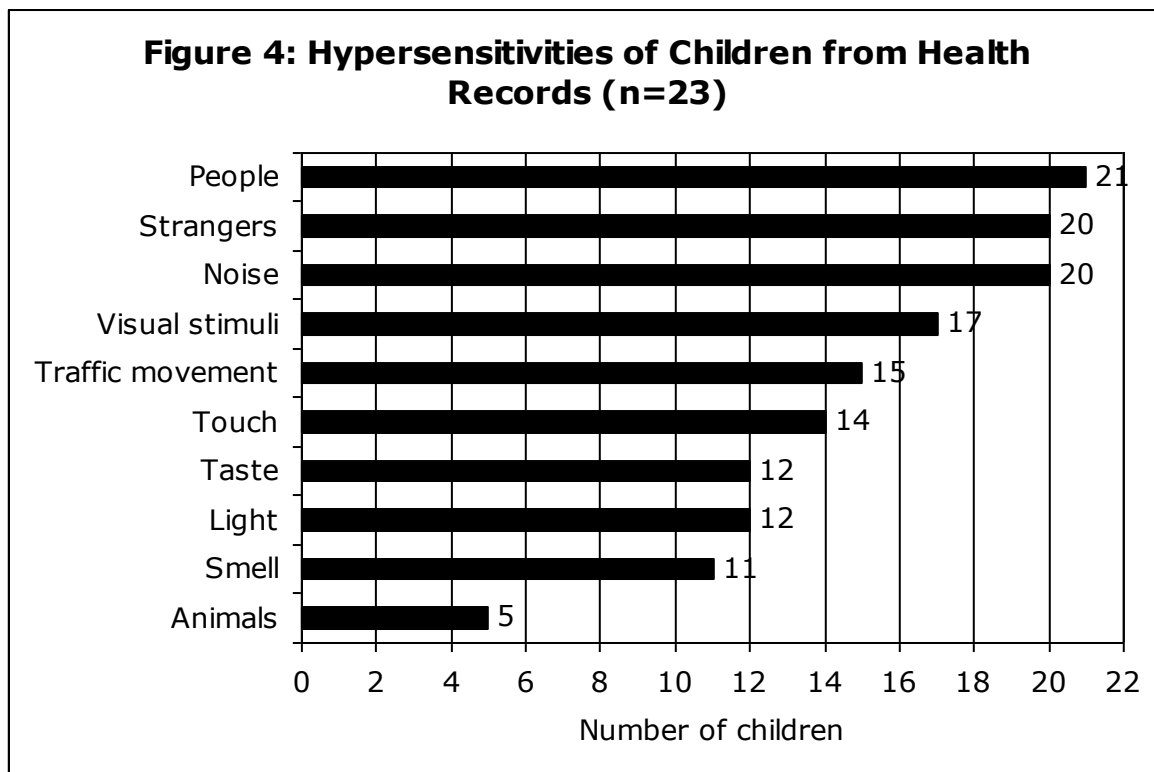
3.1.3 Impairments

The children also had a variety of functional difficulties (Figure 3). Most children (21) had speech and language impairments which were generally moderate to severe. Equally prevalent were gross and fine motor skills impairments, ranging from mild to moderate. Emotional and behavioural difficulties were present in 20 children. 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. Sensory hypersensitivities also occurred in most children (21 children) and details of these are given in the following section.



3.1.4 Sensory hypersensitivities

The majority of children had sensory hypersensitivities, with most children displaying multiple hypersensitivities (Figure 4).



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 result in abnormal and/or extreme reactions and behaviours in a wide variety of every day settings and encounters, as well as increasing anxiety, making life very difficult for the child and those around them.

3.1.5 Summary

The majority of the children had complex and multiple diagnoses. It is important to recognise that all children had complex needs, with more than one medical or health difficulty plus allied psychological challenges. All of the individuals had some condition or conditions which were severe or profound. Generally these children had severe

emotional and behavioural problems, compounded by learning and physical difficulties, to a degree which had proven unmanageable by the family, community and educational setting. As will be seen later, many of the children had been placed at CRSS after other placements had broken down.

It is extremely important to underscore the multiplicity and degree of challenging behaviour, heightened sensitivity and/or the complex level of learning and educational disabilities characteristic of these children. Their level of behavioural disturbance would be regarded as exceptionally high by professionals in the field. These children can therefore be viewed as a highly vulnerable group within the special needs population and require a variety of specialised supports.

3.2 Parental awareness of their child's diagnosis and impairments

Reporting by parents regarding their child's diagnosis and the types of challenges facing them are broadly consistent with the medical records. This was especially so with regards to primary diagnosis, compounding conditions and hypersensitivities, with noise sensitivity being most frequently noted. Parents also mentioned in the majority of cases that children had problems with language.

Child behaviour and effects on family

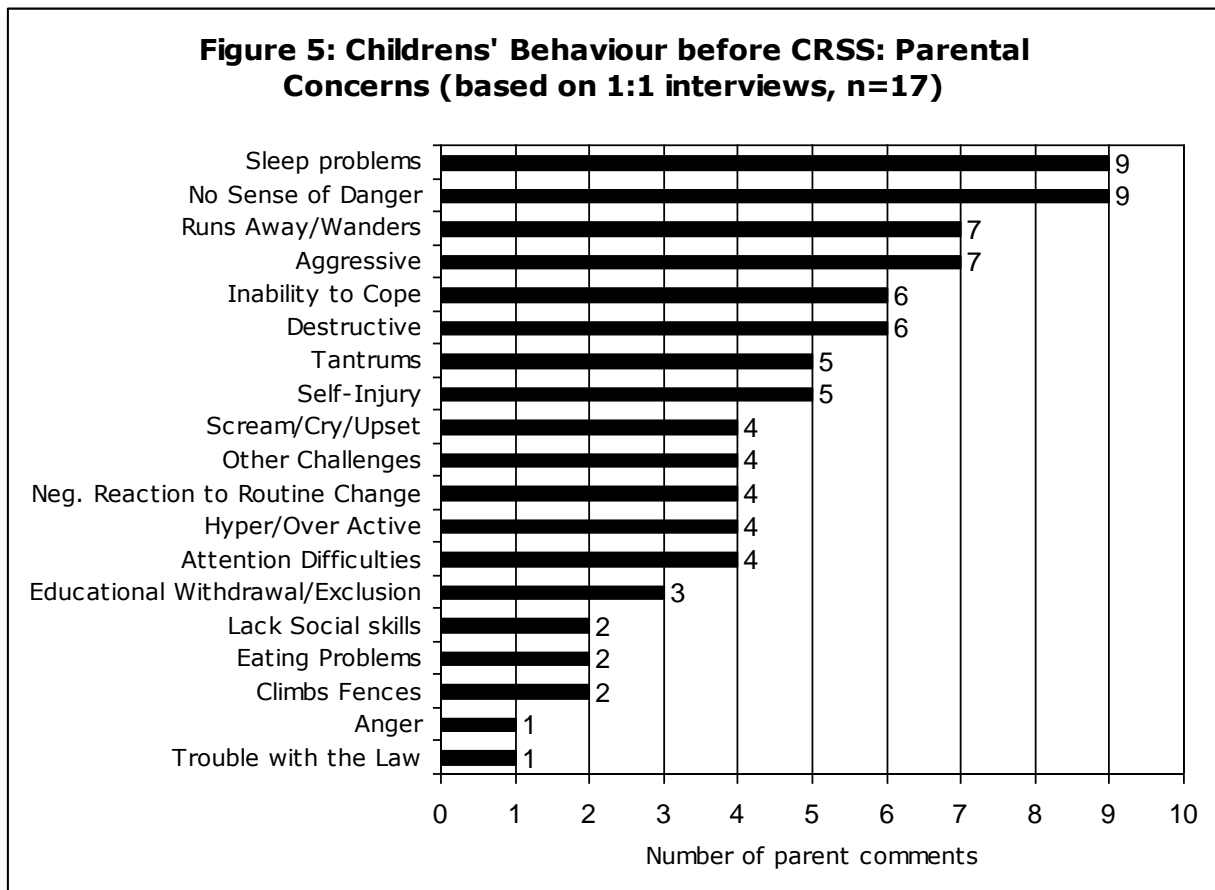
The question arises how did these children behave on a day-to-day basis prior to coming to Camphill as viewed by their parents or primary carer, and how did their families cope with the situations concerned? A further question is how are both children and families responding now that their child with a disability is attending Camphill? Sections 3.3 and 3.4 deal with behavioural and social issues in relation to the child and family both before the child went to Camphill (3.3) and the current issues now the child is at Camphill (3.4).

3.3 Child behaviour and effects on family: Prior to attending CRSS

The following section reports on parents' experiences and perceptions of the behavioural and social issues in relation to their child and family before he/she started attending CRSS. It should be noted that all children were receiving help for their additional support needs prior to admission to CRSS. The following histograms are based on the parent interviews and expanded and supported by comments drawn from parent narratives in both interview and focus groups

3.3.1 Child's behaviour: prior to CRSS

Parents expressed concern about a wide range of issues related to their child prior to admission to CRSS. As can be seen these were diverse, covering physical, emotional, psychological, social and educational aspects of the child's life. Figure 5 shows the types of behaviours which were of particular concern to parents and the frequency with which parents commented on them.



Parents from the focus group described a similar range of concerns and although not analysed numerically, the main concerns are shown below. These show a high degree of consistency with those from the one-to-one interviews.

Child's behaviour prior to CRSS:

- 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
- Noise sensitive

Collation of noted behavioural challenges

Sleep disturbances

Long term sleep disturbances were significant and mentioned by approximately half of the parents interviewed, impacting not only on the child but also on other family members.

Inappropriate sense of danger

An inappropriate sense of danger was a similarly prevalent theme which raised a number of safety issues. A lack of sense of danger, which was not improved by experience, coupled with hyperactivity, tendencies to run away or wander and an ability to circumvent safety barriers (e.g. locks, fences) gave parents acute concerns for the safety of their children, both within and outside the home environment.

Uncontrollable and unpredictable behaviour

Aggressive and destructive behaviours, self-injury and tantrums were also common concerns, with their unpredictability adding to the stress they created. Several children were reported as crying and screaming unusually (in one case for long periods). These behaviours were distressing for both child and parents, with their unpredictability and at times uncontrollability adding to the parents concerns.

Inability to cope with change

Around one third of parents interviewed also highlighted that their child displayed a general inability to cope with 'normal' life. Negative reactions to changes in routine were specifically mentioned in this respect. This inability to cope with change triggered a range of difficult and, in some children, seemingly uncontrollable behaviours, including aggression, self-mutilation and regression.

Problems with education and social interaction

Attention difficulties, hyper/over-activity and poor social skills were also mentioned. These gave rise to problems related to education and social experiences. The breakdown of educational placements was an added concern expressed by parents. Behaviours had often led to exclusion or withdrawal from educational programmes. In some cases parents removed their child because the situation was causing the child on-going anxiety.

Vulnerability to abuse

For one child there had been an experience of trouble with the law due to his vulnerability to the influence of others. This raised concerns about the future and the risk of abuse.

Parental quotes regarding child's behaviour prior to CRSS

These concerns are exemplified and lent depth through excerpts from the parents' narratives which illustrate the severity of the issues. The following sections present typical quotes from parents concerning or relating to the child's behaviour and the impact on families prior to CRSS. The situation at home for both the child and the family in the majority of instances was perceived as desperate.

Quotes from parent interviews and focus groups on children's behaviour

Having a child like [name] with a disability was a tremendous blow and we would never have realised what it was like unless we had been placed in that situation

I should add that she had very significant sleep problems as well. When she was younger up to sort of 5 hours in the night she'd be awake. And then sometimes she would – she would do things like get up, walk through to the bedroom, come up to my side of the bed when I'm lying trying to sleep, slap me on the face. Or scream, 'Go away! So we had years and years and years of taking turns to get up at night. Sometimes for long periods. Sometimes with her being aggressive, violent, or sometimes just collapsing on the floor

He has no sense of danger and he doesn't learn from dangerous situations either

He can be aggressive but we don't know what triggers it...

He never sits still he's always jumping about and asking for things, touching what he shouldn't... We've got internal locks on the doors so he can't just go into a room and start rummaging... When he's out in our garden I have to be there, I can't trust him not to slip aside for whatever reason, or climb over a six-foot fence, nothing seems to be able to keep him in.

With my wife recently he has bolted and it's taken 15-20 minutes before we've found [him] which can be quite a harrowing experience.

... his behaviour was pretty difficult to manage. He would lash out at himself and my wife, lash at his younger brother and older sister. He's got autism, severe autism... For example, he would start punching holes in walls because something, or maybe somebody had said something to him. Maybe one of the kids had tried to interact with him, and he didn't want to... His behaviour was pretty unpredictable.

When he came here he was a very disturbed self-abusing little chap, biting himself. He had no speech at all when he came and a very remote, distant little chap...

When he was unhappy before at the schools he was at. He would just be distressed. He would cry. So uncontrollable crying which they[staff at the school] couldn't stop.

Every other week there would be a different teacher, and because of that he couldn't take change very well, he just became totally uncontrolled. He would run up to this balcony, he would threaten to jump off. He would punch teachers, bite, kick, anything just to get away. He would disappear from the school grounds, as far as getting chased around the block. Across the roads. Put himself in danger, and other people. He would lash out at his sister...

He gets extremely upset if the routine is upset, you know, if there is a change.

He will regress, he is such a lovely gentle boy, 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.

To try and get his attention when there's even the smallest distraction is very difficult

And I think the situation breaking down at the school, it was a case of he has get out before he's chucked out...

Prior to CRSS he'd been in 1,2,3,4-how many schools can you count you know Four in 4 years, two in one year. Just because the education system failed him

One of the reasons [son] came to Camphill was because the special needs school he was at - they were building round about there and that's when [son] showed the most distress. He would come home bleeding because he was biting himself with distress.

Summary

It should be noted that several of these behaviours occurred in any one child. This indicates the diversity and severity of the behavioural challenges posed by these children. Their behaviour prior to attending CRSS was extremely disruptive, uncontrollable, unpredictable and sometimes aggressive in a variety of settings, including home, educational and community situations. The fact that many of these children had been excluded or withdrawn from other educational facilities is some indication of their complex additional support needs. The majority of children come to Camphill as a last resort. To give a clear picture, it is worth reiterating the behaviours of the children prior to placement at Camphill. These behaviours included:

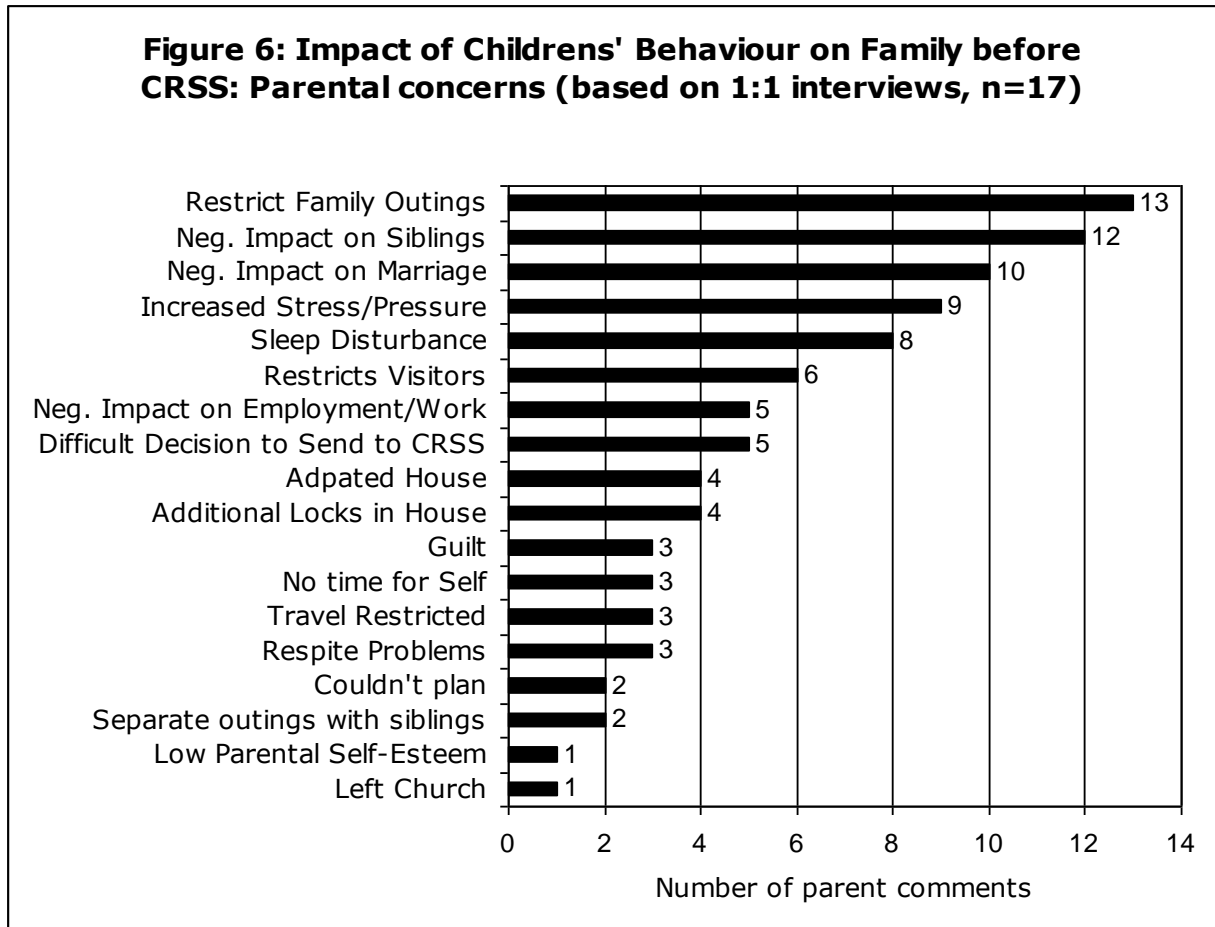
Smearing faeces	Climbing over fences
Bed-wetting	Forcibly breaking out of their home
Soiling	Screaming for long periods
Throwing	Uncontrolled and unpredictable
Hitting	behaviour
Spitting	Major sleep disturbance
Scratching	Impact of non-relevant stimulation
Self-mutilating behaviour	Inability to gain child's attention
Regression	Disrupting neighbours
Lack of a sense of danger	Negative interference with other
Rushing into traffic	members of the family

As the literature about learning disabilities, including autism, attests it is the variability of responses, along with the intensity of the challenging behaviours, which make it difficult for the child to perform and integrate appropriately in home, school and/or community (Wing, 1993; Frith, 2003; James & Brown, 1992; Humphries, 2007 & Nulman et al, 2007).

3.3.2 Impact of child's behaviours on family: prior to CRSS

The impact of the behaviours outlined in the foregoing section was not limited to the children themselves. It had significant consequences for their families as well. Figure 6 gives the range and frequency of response from parents regarding the impact of their child's behaviours on the family prior to attending CRSS. The following commentary,

illustrated with quotes from the parent interviews and focus groups, provides some insight into the lives led by families prior to the admission of their child to CRSS.



Again parents from the focus group highlighted similar impacts:

Family life before CRSS:

- No proper support
- Life focussed on child with special needs
- Work disrupted
- No social life
- No respite
- Restricted outings
- Restricted visitors
- Negative impact on siblings

The impact of the child's behaviour on the family, before the child went to CRSS, was very frequently regarded as extreme. The author's experience of children with autism

and their effect on the family is that it is often very disruptive. But the reports provided by these parents indicate the extreme nature of the disruption that is going on, and this is consistent with their feelings of desperation and the inability of other settings being unable to cope.

Collation of noted impacts on family

High levels of general stress and pressure

It was clear that overall stress levels and additional pressures for the family arising from the child's behaviors were generally high: 'Stress levels can get very high. It is a vicious circle.' These were perceived as fairly unrelenting and impacted on numerous aspects of family life. There was a sense that families were constantly under pressure, some of which seemed to be created by trying to meet the needs of their child within a society that did not always understand and accept those needs. As a result families experienced a lack of appropriate support. Parents also experienced considerable pressure particularly in social situations to protect others from their child's behaviour and vice versa. Thus, prior to admission all the families who were interviewed were coping with major and in many cases, intolerable situations for family life. These are expanded below.

Disruption to family relationships and functioning

Disruption to relationships within the family, both between parents and between parents and siblings, was commonly highlighted. Half of the parents interviewed indicated that there was a negative effect on their marriage. The majority indicated that family freedom and choices were significantly impacted upon, with restrictions affecting normal family functions (e.g. shopping), family outings and travel opportunities being particularly mentioned. When outings did take place the family were frequently split, with siblings being taken by one parent while the other stayed at home with the child who had special needs. This was at best seen as a compromise situation and one father commented it was like 'having two families'.

Parents reported that their homes had to be physically adapted because of aggressive/destructive behaviour or because of their child wandering or running from the home. In several cases locks had to be put onto doors and windows within the house. This caused further disruption to 'normal' interaction within the family. These restrictions

and modifications to family life were all perceived to have a negative impact on the family as a whole and on siblings' development, behaviour, education and social interactions

A number of parents highlighted the tendency for family life to revolve around the child with special needs, resulting in a somewhat distorted focus of life in the family. This is a very common and understandable situation in such families and is referred to in a number of research reports (e.g. Turnbull, Brown & Turnbull 2003). The energies of family members, particularly the mother, become directed to the individual with special needs, frequently influencing care and support of other family members. It was a situation which families eventually found conflicted with sustaining an acceptable family quality of life.

Sense of social isolation

There was limited or lack of social life for the family. For some there was a sense of social isolation, as visitors to the house had to be or became restricted and socialising with others was curtailed, making life extremely difficult and limited for developing siblings as well as parents. Interaction between the family and the wider community also suffered. For example, anxiety over the impact of the child disrupting neighbours and others in community settings outside the home was voiced. Some could not get away for holidays or community and professional events.

Impacts on work and career

Current and future career prospects were negatively impacted upon. Employment and work were disrupted, with on occasion a parent taking a much lower paying job to be close to home in order to give support during the daytime. Day to day, parents were often interrupted at work because of requests from service professionals to take the child away from a facility, for example, calls to bring a child home from school. There were also reports of having had to forego the opportunity to work, study and advance career prospects due to their child with special needs. Exhaustion from lack of sleep was another factor making work life extremely difficult to sustain.

Physical, emotional and psychological impacts

Almost half the parents mentioned lack of sleep as a significant impact on their well-being, exacerbated by lack of respite. Parents recorded feelings of guilt, lack of time for

themselves, and felt that their own self-esteem was damaged. There was a sense of frustration and failure when there was no sign of progress with their child despite trying suggested methods and the child was clearly unhappy

Breakdown of educational placements

The breakdown of educational placements was a further emotional and psychological stress. Many parents expressed that placements prior to CRSS had broken down or become unsustainable. Some contributory factors from the parents' perspective were a lack of understanding of their child's needs and an inability to meet those needs through:

- inadequate resources, including lack of suitably experienced staff and supportive therapies
- low staff to child ratio
- high turn-over of staff
- inflexible approach
- poor communication and lack of integration with other services.

Parents were concerned that their child was not making progress and in some instances was distressed and regressing. Some parents encountered extreme problems in accessing CRSS as a provision for their child due to resistance from service authorities. They had had to fight and for some it had been a lengthy process. The decision to send their child to CRSS was clearly for many parents a difficult one, arousing feelings of guilt and failure, which were for some exacerbated by the process of securing a placement at CRSS. Parents felt that they had to admit to failure in order for their child's placement at CRSS to be secured. That parents were prepared to go through with such 'humiliation' is further indication of the severity of the impact of their child on the family and the desperate point which they had reached.

Sense of desperation

Finally, a sense of desperation amongst family members and their inability to cope or function as a normal family was clearly identified. The degree of the child's needs coupled with inappropriate or inadequate support, led parents to perceive that the situation at home for both their child and the family in the majority of instances was desperate.

Quotes from parent interviews and focus groups on impact on family

Before Camphill we were under a lot of stress the whole time, it was so difficult for other people to understand [our son], whereas in Camphill they do understand him and his needs. I don't blame people for that if they are not in the experience of having a child with special need; ...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

In those days it was very erratic. We were very tired and not relaxed.

...these difficulties have a massive impact on the life and everything else in the family. And of course some families have two children, three children. It's not just the one child you should consider, really, at the end of the day.

We don't know how he's going to react and we can't, you know, if we want to go and buy a new carpet or something, we can't all just go off to buy a new carpet, because he may not want to go into a new shop.

I've got an older son. It was hard for him, because he felt he couldn't go out and do family things even sometimes just going out for a walk in the park. And [daughter], she would just not settle at all. She'd be very angry really at what she was going through. So we ended up we just wouldn't go out anywhere.

We can't go the pictures or bowling, things that a family normally do, so it's very limited what we can do

We just wouldn't go out anywhere

If we go out we go in the car, we don't tend to go walking. He doesn't walk particularly well and my husband has to go with him especially for the danger side of things

Ok, we weren't together as a family, but at least the kids would get what they needed to have and get the efforts and enjoyment without – but when we tried to do it together, it just doesn't work and then nobody got nothing.

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

We had to put locks on all the doors. Again, which to me was an anathema.. I thought we shouldn't be locking him out. But there was no choice. He would go in and take the things off the walls. Throw the things out of the window. So again, we got locks on the windows.

So much attention was centred around [her brother with special needs] she probably missed out a bit as far as she had to amuse herself and probably became a bit withdrawn.

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.

[Sibling's] friends have grown up being accustomed to finding the doors locked, 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 would say that before [child with special needs] came into Camphill your life really went on hold, you couldn't plan anything because so much care, even shopping at the supermarket and home again was quite a treat in getting out of the house for a while. An hour or two was the most you had to do that, everything suffers because you haven't got time for yourselves, any quality time because everything centres on time for the child, etc

When we had [child with special needs] at home, there was just a constant – everything was [her]. You know. Stopping her from destroying stuff, it was trying to calm her down, or trying to calm down her brother and sister if she's attacked them. The whole world revolved around her. In some way you want the world to revolve around your kids, but it revolved around her in a negative way...

Because until to actually lived with it you have no concept of it. Your life resolves around the child with autism spectrum disorder. You don't (have) a social life. Nothing

We were getting calls about 1 o'clock in the afternoon saying [son with special needs] is out in the playground. We can't do anything with him; can you come and get him? So then even at work, we couldn't even guarantee that we could do our normal work.

I've never been able to work because of [daughter with special needs] needing care, I've never worked since having her

There was just no way you could have studied or improved your careers prospects or anything, just impossible.

I kept him at home all the time, when he reached the age for school I kept him home...

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.

Looking back, I just don't know I managed because I was living on 2-3 hours[of sleep] a night and not getting anything during the day. So life at home wasn't fun for anybody at all. And we had no respite. Really home life was exhausting, unhappy, dangerous at times.

And this was a child who at this time- he'd never spent a night outside our bed. That was impossible.

And we tried every strategy under the sun. We had strategies coming out of our ears. We had behaviour management strategies all around the kitchen. What to do if she does this. What to do about that. How to deal with her in this situation. We took so much of advice, talked to so many people, and it still wasn't making any difference! The kind of, we thought no we've done what we meant to do. Everyone says, well do this and be consistent and do that and....it just wasn't making a difference.

One behaviour might lessen then another one would emerge. And she was also just not a happy person.... Felt like living in a battleground all the time. And living by strategies as well. so long. Somehow she just needs to live, you know?

So we decided we wanted to come Camphill, did a placement request. Had to fight quite hard to get him here.

We fought for three years to get the education system, psychology, all those people involved. Get tests, all the things done. And it just wasn't leading nowhere. ...It took three years to him to Camphill.

I was not resistant to him being here because of anything to with this place. I just thought his place was with his family. But, I think this[CRSS] is as near to being in a family situation as you can get other than being with us... I've got to concede, you know, I used to think well, come with me we'll stay together as a family. You know, sink or swim sort of thing. But I think we were sinking to be honest.

...the only way we were going to get anywhere here was really to publicly admit as a family we had failed, to admit publicly that as individuals we had failed, to admit publicly that really we weren't good enough and this kind of ritual of humiliation had to be gone through and once we'd gone through that the dear education representative at the end of the table said 'Well ok we'll fund it but it has to be full time residential'... and my immediate response to this was just to blow and I was going to leave and the dear care manager gave me a sharp kick under the table and said 'Shut up' and for once I took her advice

You're trying to treat this one as a family, but it's not working. And I think as a couple we both became a bit – I was at the desperate stage. I don't know where [husband] was -----, but we certainly weren't together all the time in what was going on

Prior to [his] coming in here, the way things were we had 26 folk coming in and out the house per month providing integrated, in inverted commas, care for him ... it was hopeless. My wife, who was the person who probably required help and respite to the greatest extent because it was her who was having to cope with the majority of the problems, was just run ragged because there was no co-ordination between what was going on. It was a multi- agency package... it was just hopeless and we knew that couldn't continue. ...we were just at our wits end with[son] and we didn't know what on earth to do next.

At times you would say, 'It's ok, he's got autism. If we just leave him he'll be ok.' And at times you get fed up trying to explain or trying to justify it all the time, I think.

We were probably far too over protective looking back but that's how you cope as a parent.

The above quotes indicate quite clearly the nature of the impact of a child with highly disruptive and disorganised behaviour. Validation of the nature of this behaviour comes

from various educational institutions and other services who often describe the child as unmanageable, hitting out at teachers and disrupting other children, as well as various forms of uncontrolled behaviour, such as running away, which is experienced by the parents when the child is at home or school.

Summary

The impact on the family relates to the experience both within the family and in interaction with the wider community. Family members were seriously restricted and unable to function 'normally'. Relationships were disrupted and there were significant impacts on employment and on sibling's education. Physical, emotional and psychological health suffered with exhaustion frequently exacerbating feelings of an inability to cope and of desperation. The added pressure of accessing appropriate provision for their child exacerbated the situation and reinforced the sense and image of a failing family. Duration of the impact on the families was a compounding factor. There was a sense, in a number of instances that the family was breaking down. If we view the lives of these families in the light of the quality of life goals outlined on page 14 it is clear that achieving these goals within the family setting was severely compromised for most if not all the families. As a result their individual and family quality of life was suffering.

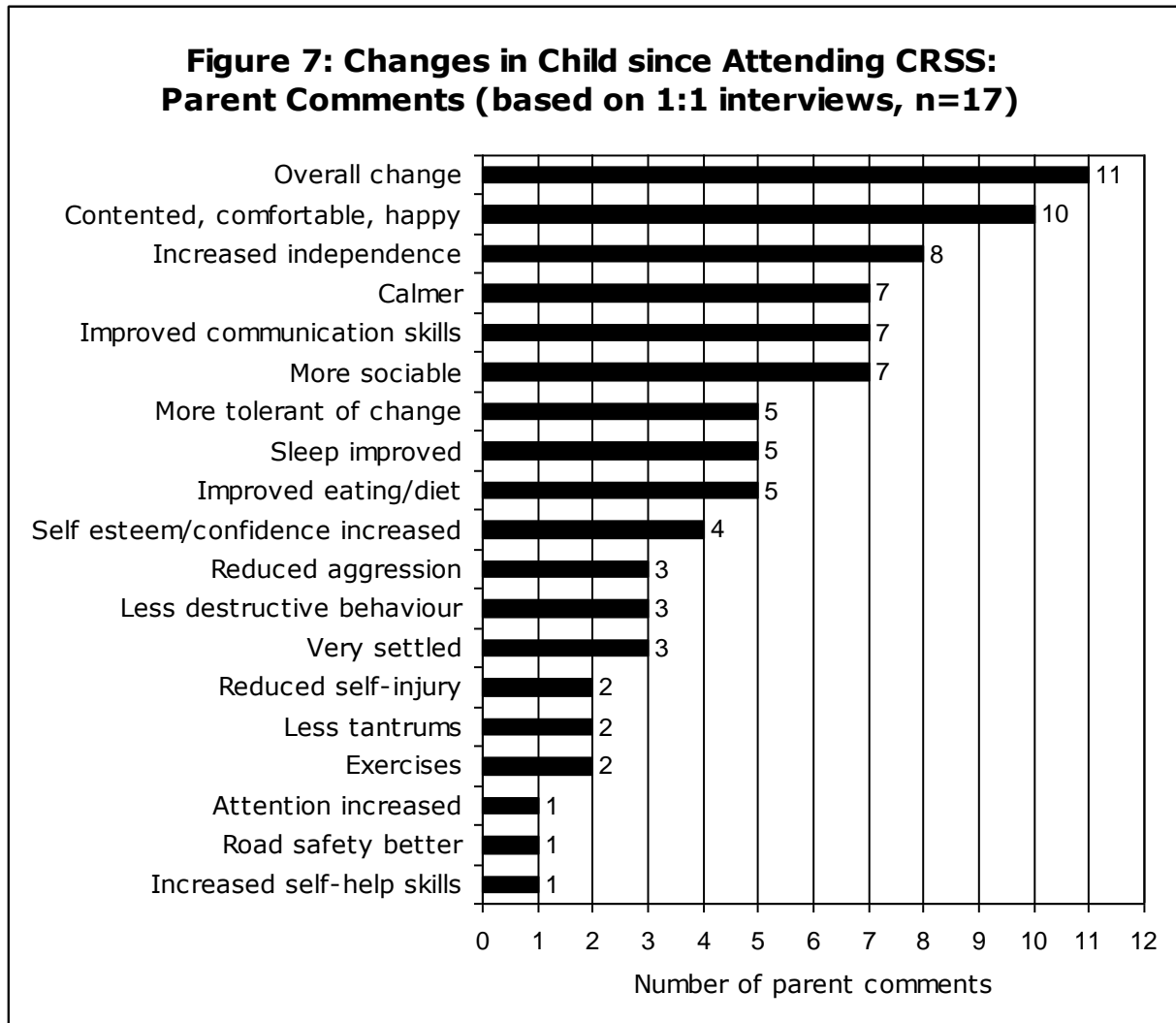
The foregoing indicates quite clearly the nature and severity of the impact on the families as a result of coping with a child with complex special needs. The impact of the child's behaviour on the family, before the child went to CRSS, was very frequently regarded as extreme. The words used by parents such as *shattered*, *vicious*, *dangerous*, and *wits-end* are of interest in that they illustrate the depth of feeling experienced by these parents as a result of the child living with them. On occasion some parents broke down in tears as they recollected these events. The author's experience of children with autism and their effect on the family is that it is often very disruptive. The reports provided by these parents indicate the serious nature of the disruption that is going on, and this is consistent with their feelings of desperation and the inability of other settings, such as school, to cope.

3.4 Changes in the child and in family life since starting CRSS

It is interesting and relevant to contrast the commentary on parental concerns regarding their child's behaviour and the impact of that on family life prior to CRSS with that relating to parents' current experience now the child has spent a while in CRSS.

3.4.1 Changes in the child since starting CRSS

Figure 7 provides a summary of the categories and their frequencies of parents' comments on the changes in their child since starting CRSS from the quantitative analysis of the parent interviews. These categories are then expanded with quotes from the parent narratives.



The 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

Collation of changes in child since attending CRSS

Positive changes

Over half the parents noted overall and positive changes in their child, and highlighted that they viewed their child as contented, comfortable and happy.

Increased independence

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 CRSS campuses, where quiet, open space combined with safety gave their child freedom to explore independence. Further opportunities to foster independence were provided for some by the proximity and accessibility of other Camphill communities via the old Deeside walkway.

Improved communication

Around half of the parents observed better communication by and with their child. This seemed to have positive consequences for improved behaviour and a perceived improvement in their quality of life, through an ability to convey their wants and needs. The following description of one child illustrates this overall change clearly:

'When he came here he was a very disturbed self-abusing little chap, biting himself. He had no speech at all when he came and a very remote, distant little chap... And now seven years later, although he's coming into his adolescence, we have a chap who can speak. I mean the last three years or so the development of speech has just been miraculous and through that his ability to communicate and let us know what he wants and when he wants has lessened the frustration he

must have had about not being able to let us know what on earth was going on in his world at all. So there's just been an enormous development in his communication and that has fed through into his behaviour calming. He's still autistic –he always will be autistic- but he is far better able to let folk know when he's enjoying himself, when he's fed up, when he's sore and that has come about, not by any magical process, but by an extraordinary relationship built up between ourselves and the house that he stays in on the Camphill Estate.'

Parents remain aware that their child's underlying condition will not 'disappear' but time at CRSS had given them evidence that it need not so severely isolate and limit their child. For this child so significant has been the improvement in his communication skills that the word 'miraculous' is applied, not in the sense of a sudden change but to emphasise the degree of progress and its ramifications for the child's and parents' quality of life.

Increased calmness

Greater calmness was commented on by around half of the parents, and in some cases this appeared to link to less unpredictable and uncontrollable behaviours. This clearly had significant positive impact on both child and family

Increased sociability

Parents (approaching half of those interviewed) also saw their child as more sociable and around one third commented that they were more tolerant to changes in the environment including people around them.

Improvement in health: sleeping and eating

Improvements in sleeping patterns and improved eating were noted by around one third of the parents. Some children showed a general improvement in their physical health directly linked to a reduction in stress levels.

Increased self-esteem

A quarter of parents commented on gains in self-esteem which for some appeared to be encouraged by the community style living where children have opportunities make a valued and purposeful contribution to the functioning of their house.

Reduction in destructive behaviours

Reduced aggression, destructive behaviours, self-harming and tantrums were also noted. The period at Camphill has resulted in improvements in the children's behaviour which generalise to the home environment. Sometimes small changes are seen as representing major strides in contrast to previous behaviours. Modifications of behaviour learned at CRSS had helped with some of the day to day problems which had occurred before.

Quotes from parents relating to child's behaviour since attending CRSS:

When we arrived at the [previous] school he would just start to cry. As soon as we turned into the road that led onto school, he would start to cry. And that conveyed to me that he was unhappy to go in there. Comparing that with Camphill – we come to Camphill now, he jumps out of the car, 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.

Before he came to Camphill he was quite unsettled in himself, now he's calmer and more at peace with everything and it's totally changed him, Camphill. He's really enjoying his life, the quality of life that he has, though it is limited-there are things he can't do- he's totally benefited.

He is now calmer after his time here, but changes causes behaviours to reoccur.

I think the fact that it is so quiet here, it gives him some degree of independence which is what we're aiming to give him, obviously, as he grows older. We want him to try to be more independent. And I think that the fact that it is so safe and quiet and here – because he has no sense of danger – and he has the ability to have a certain amount of freedom

On many occasions in the grounds at Camphill he's been able to go round and enjoy his surroundings and take some interest in them. To see him wandering across the lawn and going across to the swing and enjoying the peace and quiet means a lot to us.

He now cycles to school. He now cycles down to Newton Dee to the shop on the railway line. He skate boards, he roller blades. He does all the sorts of things. He doesn't have

to go somewhere special to do it. It's not an event to go and do it. It's not a treat to go and do it. He just goes out the front door and does it....So the security, this feeling of safety. We feel this as parents. We know he's safe here we know he's not going to get run over. We know he's not going to get picked up by folk or whatever. So there's safety.

It's [CRSS] just given us a total different way of life. And before [daughter with special needs]- you didn't know how she was going to be everyday.....since coming here she's been so calm, contented. She's just really changing to a different child completely. We saw really, within, I would say a matter of weeks, we were noticing a big difference. And ever since then it's been really quite a good response we've been getting. We can just never believe that before.

And he's also become more sociable. So, we used to be in a situation where if new people came to the door, he would run upstairs and he didn't want to mix... He's now quite delighted to see people. So his social integration with other people seems to have come on leaps and bounds since he's been here. So, just all around, he's eating better. Just a happier child. Less temper tantrums than we had before. And just things are easier.

He would bite his thumb almost in half, he can't communicate – since he came to Camphill we've never had any experience of that at all. He could become quite ill, at home he needed a lot of care, he went to a Special Needs School and it was a classroom environment rather than the natural environment he has in Camphill. Again, he showed distress by behaviour and his health deteriorated...Used to be on antibiotics much of the time but since he's been at Camphill I think he's had two antibiotics, about 36 before

The ability to contribute, in however small a way to the daily running of the household, the community in general, has developed a robustness, a strength in him that he would not have got anywhere else. That feeling of worth and purpose is something that we're going to try and establish for him in his adulthood.

I used to dread doing the zip up on her coat or on her jacket because she would always slap me while I did it, or kick me. I couldn't ever find a way around this. School[CRSS] taught her this very simple thing of she holds her hands behind her back while her zipper is done up. And now she'll do that with me. I don't have to ask her. I don't have to tell her. She just does it. So it takes an awful lot of tension out of everyday things. Just because she's learned these things at school and she does them without thinking.

We still lock the doors just out of habit, but [he] knows where the keys are now, so he can open them anyway himself. But there's not so much a panic... he'll go in and he'll just look about now.

She maybe won't be a productive member of society, as social workers might say, but she's a productive member of Camphill and I think that's what works

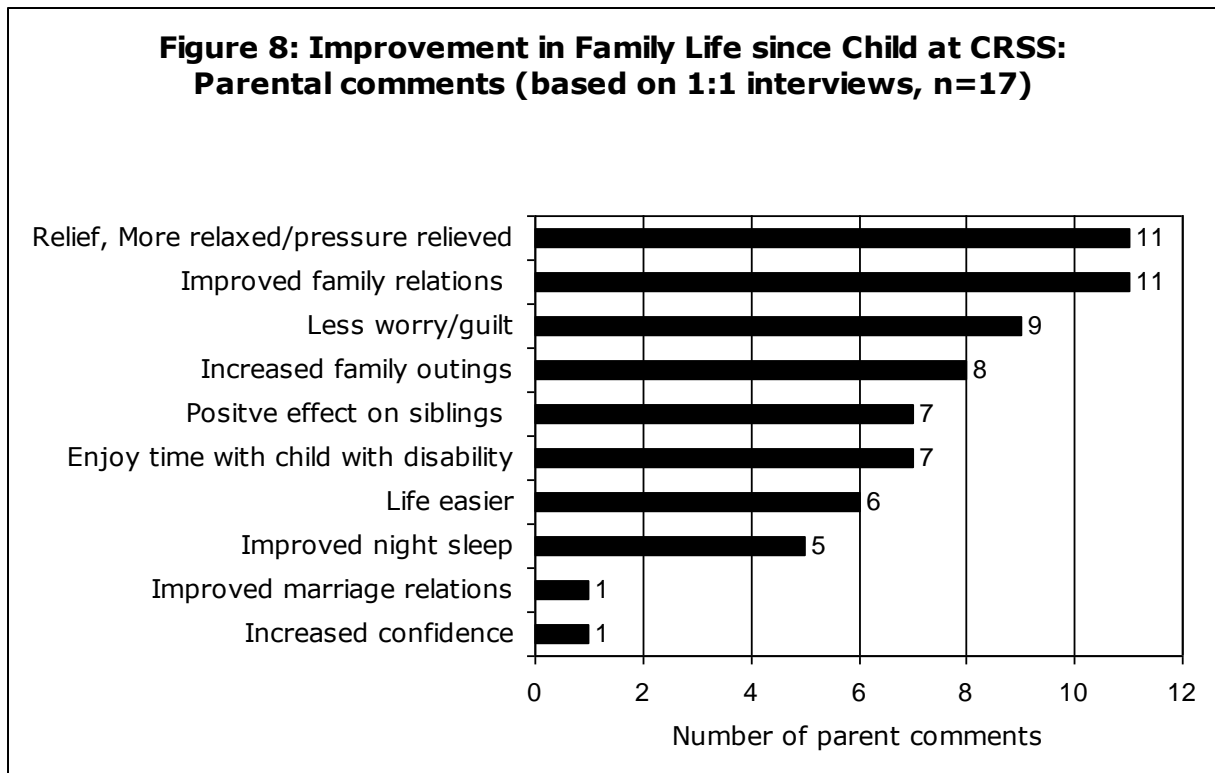
Summary

The positive impact of CRSS on their child is firmly and clearly noted by all parents. It is interesting that none of the parents commented on a regression in their child's behaviour since attending CRSS and all observed some improvement and positive development. What seemed particularly important for parents was that they saw their child happy, contented and enjoying a good quality of life. This contrasts directly with comments prior to CRSS when parents characterised their child as distressed, not coping and unhappy. Parents also highlighted positive development in communications skills, social interaction, independence and self-esteem. Also noted was reduction in negative behaviours such as aggression, destruction, self-harming and tantrums. Sleeping, eating and overall health for some were improved. There was recognition by parents that their child still has and will always have difficulties, but within the environment of CRSS their child is functioning better and has a valued place.

It seems appropriate to re-iterate some of the major comments since it is these positive changes in behaviour and development which may well be at stake if the ambient environment of CRSS is changed, for example as a result of building the AWPR close to the premises. Children are said to be calmer, but it is still noted that changes in environment can cause behaviours to reoccur. This is true of all the parents interviewed. The period at Camphill has resulted in children learning new activities which generalise to the home environment. Sometimes small changes are seen as representing major strides in contrast to previous behaviours. One should not gain a sense that children are cured, but there is a clear indication that parents see their child behaving more normally and in a number of instances the progress is viewed as very considerable. However, against this positive background parents were aware that the situation for their child was in many ways fragile and that other changes and triggers in the environment could still result in the return of previous behaviours.

3.4.2 Changes in family life since the child started CRSS

The following represent parents' views about changes in family life now the child has spent some time at CRSS. Figure 8 provides a summary of major improvement categories and frequency of comments amongst interviewed parents. Depth and expansion are proved through the direct quotes which follow. Figure 8 and the comments should be directly contrasted with parents' views when their child was permanently at home.



Collation of parental perceptions of changes in family life

Reduction in overall stress and pressure

Generally parents felt relief as a result of their child coming to CRSS. There was an overall reduction in stress levels and parents felt more relaxed having fewer worries and less guilt. Parents commented on significant positive changes in family life as a consequence. Part of the reduction in stress and feeling of relief which parents expressed appeared linked to the fact that their child is happier. This is important for parents and has an impact on the whole family.

Improved family relationships and functioning

While some of the comments reflect on the change in the child's behaviour, they also intimate changes that have taken place in terms of the parents' experience of family living. The positive change is for everyone in the family. In a number of cases the parents mentioned that family and parental relations were improved and parents felt more confident. Due to improvements in the child's behaviour parents felt they were now often able to enjoy the time that they had with their child with a disability. When the child comes home, parents and other family members seem to enjoy having them at home and are aware of the increased quality of the time spent together. Being able to enjoy time with their child appeared to reduce guilt and generally improved family relationships. Some families considered that CRSS 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.

There was a sense that family life was less restricted while the child was at CRSS allowing the family to function more 'normally'. This was evidenced by the following:

- Ability to carry out day to day functions unrestricted
- Less restriction on activities and on parent time with siblings
- Siblings are able to develop their education and social life more normally

In addition, for some parents, improvements in their child's behaviour meant that when they were at home the whole family could at times go out together. Although there are still problems, such as some restriction in family outings, the family still consider that their life is totally changed and in a positive way.

Work life stabilised

Work life was more stable and no longer disrupted by calls to pick up the child. Parents were less guilty because they felt their child was settled and benefiting from being at CRSS

Impacts on health

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

Quotes from parents about family life now child is at CRSS:
--

Family life is greatly improved...

It has improved dramatically...

We haven't looked back...

You know, the fact that he's here now, it's allowed us to sort of calm down a bit and not...you know when I think back to what I was like a year and a half ago, I didn't think I was stressed. But I was! I definitely was. But when you're living in it, I don't think you realise that.

It has totally changed our whole life. 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. You know that he's getting the best care and quality that life can give him, I think it has made everybody feel far happier.

Really Camphill has been the first place that he's been comfortable with and that he's been happy with. And that rebounds on the rest of the family, because if he's happy then we feel happy as well.

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. 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.

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

When he's up at Camphill and he comes home at the weekend, the quality of time you have is much, much better because you're not irritated. That's sounds like I'm very intolerant, but I'm just being very honest.

Camphill has transformed his life, yes it's 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. All of these things are very important.

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 just do what other people do. I think that's it in a nutshell.

It allows us to do things with the other two boys that were restricted
When he is away, yes, it does help us to be a family because when he was very young it was extremely difficult to give attention to my other two

[Being at CRSS makes]a huge difference. I have another child who is younger and it allows me spend more quality time with her, because she's had to take a back seat all the time.

His brother has been taking his HND at college so from the study point of view everything has been calmer because [son with special needs] so much calmer; prior to that the whole family was stressed. The balance of Camphill and home makes it a lot better.

I think the boys [siblings] are certainly a lot more relaxed.
And they've got more of a - much more of a social life for themselves

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[CRSS] during the week

It's just given us a total different way of life. We never went out as a whole family before. Still not often we go out as a family, but definitely more than we used to.

I'm more relaxed about him coming here. I don't have to worry about him. I can now go work without having to worry; without feeling guilty. Whereas before I would be thinking if he's unhappy at the nursery should I be leaving him there? Whereas now we don't have the guilt conscience. And we actually feel that he's benefiting from being here. Which we didn't – and before we were wondering if that was the right place for him

I can sleep! Sleep! I can go to bed and I know that I can sleep till the morning. Camphill has made a huge difference. It's exhausting looking after [daughter], 24/7, she's a big girl and she's heavy and she needs – she's not toilet trained or anything, it's hard work. She wakes up a lot during the night, we've got a TV monitor to keep track of her seizures during the night. It's [CRSS] not just meeting hers needs, it's meeting the needs of the family.

Future hopes and aspirations

Parents were also asked about the future. This was an open query for parents to say exactly what they thought might be happening in the future. Some of these comments were about themselves and their family; others related more to Camphill 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 both 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 CRSS. Some parents noted their recognition and acceptance that their child will never be truly part of a wider society. Despite this their worries were alleviated and they seem able to maintain a positive outlook for their child's future when they believe there is a continuum of service available within the Camphill system.

Parents are quite clear of their need for CRSS services and the continuing services of other Camphill communities and express fears for the future of their child if these were to be unavailable. Finally a number of parents note that, family life can still be demanding and some parents still find it difficult to have a child in residential care but the family quality of life has improved and there are signs of an ability to function as family where they were not functioning before.

Parental quotes regarding the future

Well our horizon has constantly had to lift with him. He has exceeded our wildest dreams in term of what he was going to be capable of. Our expectations are transformed. I could actually see him in work suitably supported. What Camphill has taught me more than anything is the feeling of purpose and worth that he has in his life.

To be honest, we can't really see [him] settling into a classroom situation because of his sensitivity to noise is so bad. And his concentration levels are so poor. And so, mainstream schools would definitely be out

I don't feel worried about the future, because I know that, looking here – and we live between the two estates – you can see that there is a marvellous future for him to part of the community

I imagine she will go through her youth here, and if it's at all possible, I can see her living as an adult within the Camphill estates. You know, maybe Bielside; maybe working in Newton Dee. And she would be perfectly able to have a wee job in one of the workshops. And I suppose that's my hope. I suppose parents have hopes and dreams for their children, and I have mine...

My big fear now is, if I don't get him into Camphill place for him, where does he go as far as...you know the alternative?

I find it quite frightening, if somebody won't take him, I find that quite a worrying prospect. I just hope that perhaps – I mean there's no guarantee of a place

If this community doesn't exist where will these children and young adults be going? We don't only want him looked after, it's about his happiness, otherwise we wouldn't do it.

Well, I mean it is certainly easier. There is no denying – the whole concept of having a child looked after away from the home is very difficult. And we took a long time to even consider letting her come here. But as I say, it has brought the family together. I think we are more of a family now than we were before hand

Summary

Parents see an overall improvement in their family life. Parents can engage in activities with other children in the family with fewer restrictions. Families appear to feel less stressed and as a result can probably function more effectively. This is 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 due to 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-either each evening, weekend or holiday time, depending on the situation. Family relationships are 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. 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'. The fact that the child may go away on a residential 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 CRSS] is in [his] best interests as well as the family's.'

Families perceive that the services provided by CRSS and other Camphill communities are important for the realization of their hopes for a good quality of life for their child and their family, both in the present and in the future.

It is extremely important to recognise that for every 50 children in CRSS there are generally two parents and at least one sibling. Thus for every 50 children in Camphill there are 200 members of the nuclear family whose lives are critically and positively affected by the child attending CRSS with positive effects on quality of life for all.

3.5 Important features of CRSS: Parent's perceptions

Parents gave a range of responses to the question: 'What do you think is important about CRSS with regards your child and family?' The key themes which emerged included:

- Quality of the environment
- Integrated and inclusive approach of CRSS
- Valuing of the individual

- Quality of the personnel
- Uniqueness of the resource

These are explored more fully below.

3.5.1 Environment of CRSS

Tranquillity

Almost all the parents commented on the quality of the environment of CRSS highlighting the peace, calm and tranquillity as an element in their child's well-being. It is hard to get across to people, who do not know CRSS campuses and have not stayed there, the nature of the environment. It seems the tranquillity and peacefulness affect most if not all those who encounter it, for example, 'Speaking of the tranquillity, it is very strange, but everybody says that...and it's most beautiful.' The researcher had the fortune to experience this when he stayed there.

Freedom with safety

Associated with this tranquillity was the notion of safety, freedom and the fostering of independence (as has already been noted). Parents considered that this presented opportunities for their child to integrate with the wider community.

Therapeutic value

A number of parents emphasised the safe, quiet, natural outdoor environment of CRSS as a significant factor in their child's improvement. Extensive use is made of the outdoor environment as part of the educational and therapeutic programme, especially for children who do not cope well with the classroom environment, as well as for recreation. For others the peaceful environment was perceived to help their child to benefit educationally within the classroom setting.

Parental quotes on environment of CRSS

It's a good place for my daughter, it took a long time to find it and it's ideal for her, it's peaceful, it's tranquil, a safe environment, the people work well with her, she responds well to them, and right now she's doing fine.

the grounds are very settled and beautiful, I guess tranquil is the best way of describing it. To see him wandering across the lawn and going across to the swing and enjoying the peace and quiet means a lot to us, and although we have a garden at home it's not quite the same because we have to be with him all the time, because three steps and he's out of the gate and could be under a car.

Camphill is a place where he's safe, safety is important.

This is the main thing I feel it extremely safe, tranquil but at the same time it has communication with the outside world you know. It is not just Camphill, they go out, you know, they go to Newton Dee, they go to other shop with the staff and this I find they often see, they are sheltered in a way but there are often people from the community who come to Camphill just to the café

Parent: I think just the outdoors, she just loves being outdoors. She couldn't be cooped in a classroom all day, you know.

Researcher: So how often does she go out?

Parent: She plays out most of time, I would say.

As far as [son] benefits are concerned his level of 'being grounded' has improved dramatically over the years he's been here and we now really do feel that the setting is adding an awful lot to his educational side being up here in these tranquil surroundings. The atmosphere here in Camphill has helped him settle in school and he is certainly very happy here

3.5.2 Inclusive and integrated approach of CRSS

From parents' commentaries it was clear that it was not necessarily any one factor that led to the improvement in their child but the inclusive and integrated approach of CRSS, supported by the environment. Parents see their children embedded in the community of CRSS which, in addition to the personnel and their families with whom the pupils share a house, also encompasses retired personnel. This integrated approach of CRSS involving care/living situation, education and therapy was mentioned by a number of parents and was clearly one of the elements which they perceived made a difference for their child, allowing continuity between 'home' and school within a community setting.

Some parents highlighted and valued the attention paid to the acquisition of life skills as part of their child's education at CRSS as well as the opportunities for social development through extra curricular activities and community living. This was seen to give their child experiences which could prepare them for a future role within society.

Parents experience that not only is their child fully accepted and included within CRSS community but they as parents are too. Further this community is one which adds to, rather than detracts from, their sense of purpose for their child's life. This contrasts with the parents' experiences in the wider community.

The opportunity for their child to access a variety of therapies not available in the outside educational system was also valued by parents. While, for example, parents may recognise that in regular schools personnel did their best for their child, they nevertheless felt that CRSS had other resources, including on-site medical personnel, which made an important difference.

Parental quotes re integrated practice of CRSS

For our son in particular the attention he gets, the environment, the whole classroom situation, is absolutely superb

And there's no doubt in my mind that it's the whole package, if you like, is what's made the difference to her... If I'm trying to explain it to people, they just think of it as a school building. People who go in and out, on and off duty. And I try to explain, no. What makes it different is it's peoples' homes. People live there. And she [daughter] lives there as part of that community. So definitely the community is really important.

There's peace here. There's consistency here. I don't know – I suppose it's a different lifestyle

And the holistic thing is-we're just not looking at their education 9:00 to 3:00, you've got helping them to learn to look after themselves in the morning, getting into a routine. You've got all their extracurricular things that they do after school and... I don't know, there's just the social interaction...children in their homes and everything.

it's a much more holistic approach. And it's not just about education. It's about making these children fit for doing something else as well. It's about helping them fit in. It's about...the child as a whole, you know. For example, my son, who would never have gotten the opportunity to do gardening or to help in the kitchen or do other tasks in a normal school week. He just wouldn't have had access to those types of things

Some teachers, learning support, they say "oh how can you say special schools are inclusive?", They always say it is exclusive. I say, well you don't have a clue. I have never seen people with Fragile X or Autism fully included in mainstream education because I teach there. They are not integrated, they don't take part in activities, to after activities, extra curricular activities, they in the school whereas in Camphill they are fully included.

It's the lack of purpose I think in folks lives that is really a significant determining factor in the quality of somebody's life. You have to be able to give to, have to be able to feel part of, something and useful at something to give you a quality of life. I'm convinced of that –and that is achievable in this kind of environment. I haven't yet seen it being achieved in the 'community ' When he's at home with us we are integrated in the community and we get an awful lot of kindly support in the community. At the very best we're 'That's the family with the handicapped child. What a shame' That's as good as it gets. Here we're his mum and dad. Here we're accepted. Here there aren't barriers.

They have limited resources and they do not have the type of therapies that Camphill have or can get access to.

3.5.3 Valuing the individual

Within the integrated approach of CRSS parents frequently identified that their child was treated as an individual. This was valued highly by parents. Individuality of approach coupled with the flexibility to respond to the needs of the child and their parents was seen by parents as significant for their child's development. Parents perceived that respect for and acceptance of their child as an individual, no matter what their disability or the unusual behaviours displayed, was an underlying principle on which CRSS was based and which they experienced being put into practice.

Parents experienced that their child was recognised and understood by the personnel at CRSS in a way which differed from that previously encountered in other support services. The difference seemed to be that their child rather than their disability took priority. Parents considered that this was a prerequisite for meeting their child's needs. Parents observed that personnel at CRSS approached their child first and foremost as a unique individual and worked with the child to meet his/her needs and draw out their potential. This combination of respect, acceptance and appropriate support was viewed as key to helping each child realise their full potential.

These underlying attitudes, as well as the change in their child's behaviour, influenced the parents' views of their child. The acceptance parents experienced at CRSS seemed to enable some to more fully accept their child: 'I find we wouldn't love him so much, he wouldn't be so loveable, without Camphill's help.'

Parental quotes on valuing the individual

We have a whole community. But within that we have individuals. There's no one solution. You can't press a button and it will work for all the kids.

I think in a normal school the structure and format can be quite rigid. And here it's a lot more flexible. Works around the individuals we've all been seeing. And that's I think of paramount importance to make and to help our children grow and reach their full potential.

The first time we came here [he] for no particularly good reason had decided he would attend the interview wearing his granny's red high-heeled shoes. He would have been

about six at this time. So we had a lot of concerns and again we walked in here and then the only comment it raised was 'nice shoes' and we carried on from there. So you know there was no hint or suggestion of behaviours not being appropriate. Whatever there was, was accepted and they were looking at the person behind that.

And also the seeing the children for who they are, rather than the problems they bring or the disabilities that they have. Many people might say that the social workers see the disability and there will be other people like support workers who see the problems and how they are going to deal with them. But at Camphill they see the person. And I think that's what makes the difference too. It is, for me, it's like having extended family. Because if I go to a meeting, - when the school talk about her they talk about the person I know. When the social worker- and good knows who else talks about her, they talk about someone I don't know.

They do different things with him, not classwork as such but things which help him to be who he is, he has a lot of problems with touch – being touched, getting his hands washed, so they are working a lot with him with different types of materials – soap bubbles, or play dough, or real dough in baking. We feel that Camphill look at him and see what he can achieve to help him on that path.

They [CRSS] get the best out of their pupils and out of anybody I would say because they respect the person but at the same time they guide them towards their best, the best they can be.

This is not an experiment with people, but this is a place where it helps and it makes people work and function.

3.5.4 Quality of CRSS Personnel

CRSS personnel were held in high regard by parents. They were viewed as caring, professional, consistent and worked well together as a team. These qualities seemed important for parents to feel confident that their children were in safe hands. Trust had clearly been built up between the families and CRSS personnel and this was significant for parents given their previous sense of desperation.

Consistency and continuity of personnel were also important features of CRSS, particularly for children who did not cope with and responded negatively to change. The opportunity for the same personnel to work with a child in both educational and living environment was identified as a significant advantage. In addition to the continuity of personnel, the consistency of approach, strengthened by a shared value based was perceived as an important factor in their child's improvement and a difference between CRSS and other service providers. For some the high staff to child ratio was also important.

Further, parents felt supported, listened to and involved in the life of their child through the attitude and practice of the CRSS personnel. They felt they had a voice, and for a number this was in stark contrast to their experiences prior to CRSS. The trauma of having a child in residential care was to some extent relieved by this type of relationship with the CRSS personnel. This type of inclusion was clearly valued by parents.

Parental quotes about CRSS personnel

I can't speak highly enough of the staff. They've just been excellent...

The staff at Camphill are all very, very caring, it's more than just a job to them it's their whole life, their whole community... there's no animosity, no someone trying to be better than anyone else, it's very shared, very equal and everyone cares about everyone else.

Having a child like [son] with a disability was a tremendous blow and we would never have realized what it was like unless we had been placed in that situation, again I can only say that if it weren't for Camphill I don't know what we would do. It does change your whole life and having someone you can rely on and trust with your child is really important. It's just lovely to have shared care that you can trust and depend on

She doesn't like new environments, likes familiar things, she likes the same things, no change...She's had the same workers [personnel] for two years

Parent: I think the important thing for her is she's got the same co-worker in the kindergarten and in the house. I think that makes a big difference, because before it was different people all the time....

I: Is that one-on-one?

Parent: It is, yes. And before, she did have a one-on-one, but it could be a different person every other week. It just didn't work for her. She needs to know someone before she'll even start interacting with them.

There's a shared value base. And I think that makes a difference too. And I'm thinking of other situations that [daughter and son with special needs] have been in where there have been workers who come and go, it isn't the same. It's[CRSS] just people are working in the same way, sharing the same approach of how they work with the children. I think that's kind of hugely valuable

We're in a situation here where our children are getting lots of care, lots of good professional people working with them. Not only one-to-one, but sometimes on a 2 or 3 to one. And you're just not going to get that anywhere else.

I find that staff work very well with us parents. It's not a case of they've taken over. They're willing to listen...

It's like having extended family

...one thing they do at the kindergarten is celebrate certain festivals throughout the year. And we're all invited in, all the parents are invited in. So a few weeks ago there was a harvest festival, and we all came in and we had bread that the children had made... So I think it's not just the kindergarten is just for the children, but it's almost for the whole family

the caring of the staff, they really care for everyone and they understand everyone, the staff all seem to get on really well and communicate and involve everyone. If you go to Camphill for anything, whether it's a puppet-show or St. George and the Dragon Day or anything like that, everyone's included, everyone's a part of it, it's that feeling which makes it so relaxed, and [son] has settled so well in as we really feel part of the community of Camphill. I think everybody does.

These comments speak to the quality of the staff, their dedication to their work, the way they work together and value each child equally. The respect for the individual person and the creation of an extended family life atmosphere is referred to. Also, interaction with the parents is seen as a very positive feature. The child's disability and unusual behaviours are accepted and these attitudes influence the parents' and children's views of themselves.

3.5.5 A unique resource

Finally it was apparent that CRSS is viewed by parents as an exceptional resource. This was based on an assessment that the approach is both holistic and progressive. Further, it is one of only two such resources in Scotland and the only one of its type in the north east. Many saw CRSS as the best possible placement for their child. They perceived it as offering their child the best chance to realise their potential and enjoy a good quality of life. Some parents considered that the quality of life was higher for their child in CRSS than at home, due to the difficulty of parents to meet the needs of the child in the home setting. This was clearly a painful realisation.

Although some parents were not always able to fully articulate which elements of CRSS made a difference to their child, they perceived their child was in a sense more fully 'themselves' as a result of being at CRSS. In conclusion it seemed that whatever elements of CRSS were highlighted as important - environment, integrated approach and personnel - what was created at CRSS was clearly more than the sum of its parts. As one parents put it: 'A lovely place where humanity is being celebrated every day in that school; miracles happen every day.'

Parental quotes re CRSS as a unique resource

Camphill's way in advance of this going on elsewhere. And it's a holistic approach. Which is very unique.

There isn't a bunch of similar places to this, that are in Aberdeen, or even north in Scotland or whatever.

It's the first nursery that he's been to that he's really settled and been comfortable with

For our children, many of our children – there isn't any other choice but Camphill for our children to fulfil their potential

Even being the best parent in the world you can't stretch yourself and you can't possibly give the quality of life having your child at home in the community that you are having in Camphill. As much as it can be quite heart-rending to make the decision to put a child in Camphill you've got to do the best for your child as far as quality of life is for them

I don't know what Camphill does to make her [child with special needs] the way she is. Something within the Camphill community here has allowed her – she's still very autistic, and we're never going to get beyond the autism. But she's now a little girl who has autism, whereas before she was an autistic who was a little girl, if you see what I mean. The autism was blocking – well, not like a I know what we have now with her is as close to what she always was, but just couldn't get out.

3.5.6 Summary

For parents a salient feature of CRSS was the quality of the environment, with it's opportunities for building independence and integration with the wider community. The inclusive, integrated approach embedded in a community setting was further seen to

enhance opportunities for their child to realise their potential and for parents to experience greater inclusion in their child's life. The quality of the personnel, their dedication to their work, and the consistency of approach, unified by their underlying ethos were identified by parents as important to the way they work together and value each child equally. The respect for the individual person and the creation of an extended family life atmosphere were viewed as key components. Parents viewed CRSS as being highly versatile and unique in terms of its holistic approach which they considered supported their child and their family.

It is interesting to note that despite opportunities to provide negative commentary about CRSS none of the parents did so. My impression is that parents are so relieved to finally get the type of help and support they need and see the dramatic impact on their child's quality of life and on their family life, that they have only positive comments to make about CRSS. This of itself highlights the importance of CRSS in its current environment and condition.

This section is very much related to the preceding commentary. Family members see their child settled and comfortable. The over-riding impression is that CRSS has rescued the families, for without CRSS as one parent put it, 'I don't know what we would do.' The effect of CRSS on the whole family life is also noted. It is also apparent that CRSS is viewed by parents as an exceptional environment. CRSS is also seen as a place that employs a variety of therapies that are not available in the outside educational system. While, for example, parents may recognise that in regular schools personnel did their best for their child, they nevertheless felt that CRSS had other resources, which made an important difference. Finally there is a view that CRSS is unique. There are other places like this that exist, and there are other communities that have Camphill or Camphill-like centres. It is nevertheless true that CRSS is highly versatile in terms of its range of therapies and in terms of its holistic approach towards support and treatment, including the care for families. Again, it seems very important to ensure that such programmes can carry on in the manner that they have built up over a long period of time.

3.6 CRSS: its relationship with the local and wider community

A variety of rather contrasting views occurred, and this may relate to where parents live in geographical relationship to the Camphill communities, Aberdeen. For example, one parent states, 'I didn't know very much about Camphill until my son actually started here.' Another parent, who obviously visits the area around Camphill or may live there, states:

'We see a lot of people [with special needs] around the estates, see them down there in the shop or in the pub once in awhile. They are very accepted around here. Very integrated. But 3 or 4 miles away people don't know that Camphill exists.'

This comment itself, and it is one that was expressed by a number of parents, relates to the integration of CRSS and the other Camphill communities in the local community which is seen in this case to be very positive. The parents interviewed also see CRSS as being well accepted within the surrounding area, a point being made in relation to CRSS's actual location. It is partly what it is because it has grown up within a relevant and knowledgeable community in terms of villages, visitors and neighbours. There was also an indication that CRSS has grown and is now much more outward oriented than it was previously: 'I think previously the community was much more looking within' and, 'Certainly in the last couple of years it has opened up much more and there is much more active communication with the local community.' There is some recognition that Camphill is part of Scotland's heritage and that alone makes it worth preserving in the form that it is. Perhaps adding some understanding to the dilemma that is posed for society one parent says, 'and you know it's a difficult balance, isn't it? Because as parents we all really see the benefits, etc.'

Collation of comments regarding CRSS and the wider community

3.6.1 CRSS and the local community

Parents were aware of the protected nature of the CRSS community, seeing this as necessary for the type of children for whom it provided support, but yet also expressed a sense that CRSS was integrated within the wider community. Parents seemed to perceive that this integration was fostered by a number of factors including:

- The historic and longstanding embeddedness of the Camphill communities within the locality

- The proximity and ease of access of the local communities to the Camphill communities
- The interrelationship between the local Camphill communities

These were all viewed as positive attributes which facilitated opportunities for their child's integration within a wider, yet somehow still sheltered, community outside the CRSS campuses.

Of particular relevance for the integration of their children was the connection between the CRSS Camphill and Murtle campuses and the Camphill Newton Dee community for adults with special needs via the Old Deeside walkway. Parents valued the opportunities for independence given to their children through this linkage, with children cycling or walking to Newton Dee with its café and shop, where interaction with people from the local community and even further afield could take place. The Newton Dee facilities were seen as focal point for interaction between the general public and individuals with special needs, allowing people with special needs to be seen providing a service to the wider community. Parents considered that such facilities aided acceptance and integration of people with special needs into the local community.

With regards to understanding of the work of the Camphill communities the overall view was that people not directly connected with CRSS or the other Camphill communities may have a broad idea that Camphill works with people with special needs. However, a number felt that the majority, including many of the parents themselves prior to their child attending, had no real knowledge of the work they do. Despite this, parents perceived that the Camphill communities were positively integrated in the local community and that Camphill's presence in the locality had given opportunities for the community to accept people with special needs, educating and enriching society. There was also an indication that Camphill has become more interactive with the local community than in the past.

3.6.2 Part of Scotland's heritage

As well as being a valued part of the local community, some parents viewed Camphill as part of Scotland's heritage. In that wider context they expressed the view that CRSS and

its service should be a source of pride both for Aberdeen and Scotland and given greater recognition.

Parental quotes about Camphill and the wider community

It's a world within itself, but it's a world, it's integrated in the world as well. It's nice – I think it's a comfort. It's a shelter when it's needed.

.. there's so much expertise and knowledge here, which has evolved with the location.

My imagining is that all Camphill estates are quite symbiotic.– it's all quite symbiotic, and they all they need each other. They are separate estates perhaps, but they are all one, if you see what I mean.

He can actually take himself down there, the railway line, from Camphill village where he's at, on his bike. It gives them a good opportunity to kind of feel that they can go somewhere and it's safe, it's confined. I think, for them, it's a way of kind of going out

I can see the difference, and I know the difference [between CRSS and other placements]. And I think it's because it's a big huge community, and the children travel between communities. And the community [for adult with special needs], Peter could have come and used the shops at that within the community. And have integration and acceptance.

I think it's integration. We've also got people outwith the school community coming into Camphill. You promote integration. You promote acceptance. And you promote just knowledge of people with disabilities. It's accepted.

To me it's serving a need in the community that I just think is wonderful. And it's the integration of the community with the shop and the coffee shop.

In the community, Camphill is known as the place for the most severely affected children.

I didn't know very much about Camphill until my son actually started here. Most of my colleagues have not a real understanding of actually happens within the community. But they highly value the shops they have and that they can go out have a cup of tea there.

I would have to say that the community – those communities would become poorer if the integration wasn't the way it was. I think you've got a lot of children grown up who, you know, they're getting everything thrown at them. Great holidays, all sorts of different things. Same with the adults. And I think for them it can be quite a humbling experience to be amongst these type of children and adults. And I think it actually makes those communities a richer place to live in.

We see a lot of people [with special needs]around the estates, see them down there in the shop or in the pub once in awhile. They are very accepted around here. Very integrated. But 3 or 4 miles away people don't know that Camphill exists.

I think things have changed. I think previously the community was much more looking within. And I think over the last 5 -10 years, certainly in the last couple of years, it has opened up much more and it is a much more active communication with the local community

This is a jewel in the crown of care. We're very fortunate in Aberdeen to be able to host something like this for the people of Scotland.

I mean it's something that Scot's should be proud of.

...it should be an integral part of our heritage and it should be something in which we cherish. And of course we all have first hand experience of it, because of our children. And the reality is that if we look outside our own experiences, and look at people who have so-called normal lives,- and their exposure to Camphill is very limited. I think Camphill can do a much better job of promoting themselves.

3.6.3 Summary

The parents interviewed see CRSS and the Camphill communities as a being well accepted within the local communities, a situation which has developed through 65 years of association, fostering opportunities for interaction between the local people and those within Camphill, especially in more recent years. Parents perceived this as a positive and to an extent 'safe' and somewhat sheltered situation into which their own children could begin to integrate and develop independence. They also consider that it has a valid place as a valuable service for children with special needs in the national arena.

There are those who do not see places like Camphill as part of society. This may partly arise from a lack of understanding of its work. This is something that needs to be looked at much more carefully. Certainly, as expressed by the parents, CRSS and the Camphill communities are seen as an essential part of the spectrum of provision for children and adults with special needs and an option which should be valued and supported by those in authority.

3.7 Parents concerns about the proposed road⁷

⁷ This section of the report took into account the original Murtle option of the AWPR. The route has of course now been changed. Yet the general concerns expressed are seen to apply to the current proposal although

All parents were aware of the proposed Murtle option for the AWPR (planned to run close to and cross the existing entrance of CRSS Murtle campus) and voiced a number of concerns. These were largely focussed on the impact of the road on CRSS and in particular on the children attending it. The main concerns were around disruption to the current environment of CRSS, restrictions to freedom and the impact of both on their child's quality of life, both during the construction and the operation of the road. The following emerged as the main concerns for consideration.

3.7.1 Disruption to environment of CRSS

Most parents perceived that the road would have a negative impact on the current environment of CRSS, particularly the quality of the tranquil atmosphere which they had already highlighted as a significant factor in their child's well-being and progress at CRSS. The single factor most commonly commented on in this regard was the increased noise from traffic (and machinery during construction) but there was also concern regarding increased levels of activity around the estate generated by the road.

Some expressed the view that noise couldn't be fully mitigated and there was concern that even with mitigation any increase in noise levels would damage the tranquillity that parents perceived was so therapeutic for their children. Parents whose children used the outdoor environment extensively expressed particular concerns with regards the inability to protect the outdoor environment from increase in noise levels. For one parent this was not a theoretical consideration having had previous experience of such construction noise impact negatively on their child at their previous placement. This parent also highlights a valid concern that once the impacts on the children are fully apparent it may be too late to prevent the damage.

3.7.2 Restrictions to freedom

Parents perceived that the road may well restrict the use of the outdoor environment both within and outside of the campus. This was seen by parents to have detrimental impacts on the freedom/independence their child already had achieved and on future opportunities for their child further developing independence. There was fear, justified or

it is recognised that there may be a difference in the degree of impact. The researcher has visited Camphill Estate on two occasions to consider the parents' commentary in relation to the new route.

not, that 'once the road goes in any chance of them being independent would be removed.'

There were misgivings over restrictions in freedom to move between the Camphill communities via the Deeside walkway and one parent expressed doubts that her daughter would be able to traverse the proposed bridge over the AWPR to retain the integrity of the walkway, due to fear of traffic.

Safety was also an issue with parents perceiving that the road would decrease the sense of safety for their children both within the campus and in moving between the Camphill communities. Some also highlighted that the proposed measures to increase safety, such as perimeter fences, were a regressive step in the provision for special needs, reverting to a type of institutionalised situation.

3.7.3 Impact on the child

The impact of these factors on the child's overall quality of life was of concern to parents, with particular fears that their child's behaviour would regress, bringing back all of the problems that the family has faced in the past. It is extremely important to recognise that many children had made very considerable progress since attending CRSS with positive and tangible impacts on their own and their family's quality of life. Parents were clearly concerned when they perceived this to be jeopardised. As one parent said: 'You know, it's a terrible price to pay from a human perspective for a road that could be placed elsewhere.'

Once again for parents uncertainty about the future of their child was raised if the AWPR were to be built. While all expressed a wish that their child continue at CRSS some voiced concerns over whether that would be possible if their perceived changes to the environment were to materialise. If the lifestyle of Camphill became transgressed and the levels of stimulation deteriorated some parents felt that they 'could not leave their child there any longer', while others felt that they would really have to consider whether they could keep their child in CRSS if that child was going to be in a setting that was within 100 metres from the new road. For some this posed a real dilemma, since neither could they contemplate returning to the situation that they, their family and child had been in prior to the placement at CRSS. It was not simply a matter of the impact on their child, but on the whole family, which some felt would again be a breaking point.

The concerns and fears were palpable, both for their child, who they believe deserves a high quality of life with maximum well-being, and also for themselves and their family as a whole. Most parents did not know what they would do. Many questioned why the lives of vulnerable children and their families should be put at risk, querying whether human life is less worthy of protecting than rare species of plants.

Parental quotes regarding the impact of the AWPR

I think it will be very, very destructive to the life in Camphill, if you think of a major road then you have this constant noise of traffic which never stops, ... the road would affect the quality of life of people in terms of noise, pollution, in terms of fascination and fear for the residents

Any level of sound reduction to me would not maintain the tranquillity that there is now

I think that the peace they try to create in a Camphill place is extremely important. and that would be damaged to a large degree by the constant impact of a road... in terms of constant interruptions of the life with the noise, I would expect the peace in the place to be a lot less and therefore the therapeutic environment would be decreased quite a bit

You can't double glaze a swing, or an outdoor play area. He spends a long time in the sand pit so that is tranquillity. Inside the house, fine, double glazing reduces some noise from outside, but the beauty of this site is that you have the grounds and can use them, and he is the kind of child who uses them most

I don't think it would be a good move at all because it will affect everybody within Camphill, I think the noise itself will have an overall effect. One of the reasons [son] came to Camphill was because the special needs school he was at they were building round about there and that's when he showed the most distress.

He would come home bleeding because he was biting himself with distress, he couldn't communicate really to say what was going on. If they go ahead with the road it is going to be too late when they do see the effects and now is the time to reconsider it because it's not going to do anyone at Camphill any good whatsoever

And now we've got to the level where he can come out of the schoolhouse on his own, up to the road..., but he can come out and get in the car without anybody with him. That is a marvellous thing for him to do, and I cannot for the life of me say how I would be happy if that freedom was denied – if that road was built, then you don't know, it might be like bees to a honey-pot – all the noise, he might not like the noise but he might be attracted to the noise, and that ability to let him go out of the house and to walk across to

the school would no longer exist. It would be a constraint, and one of the fundamental advantages of this place is the freedom the children have.

The one question I haven't yet had answered is exactly what would happen with the old railway line because at the moment that is a valuable conduit between Murtle and Newton Dee and I know that he certainly enjoys cycling along, it is peaceful and a good few hundred yards away from the North Deeside Road. What happens when you have a dual carriageway going through that?

Well I suspect it will become just a far less attractive environment to be in. The role is immediately changed I would suspect so there's going to have to be an element of containment just from the point of view of safety.

Let's not forget that these children have to come home to us, as parents. And I can imagine that the progress that all our children have made, it will regress. And we will be faced with a situation whereby we've got them lashing out on a more regular basis again. Their behaviour will become more unpredictable.

If the situation changes at Camphill, I don't know if where my son would go. Because I wouldn't be able to cope with his behaviour at home and the effect of family life before he came to Camphill was very, very difficult. He was very, very aggressive. I don't know what would happen in the future. I would have huge concerns about it.

I honestly don't know how you would keep an autistic child in this setting here a hundred metres from a road. I don't think you could police them, I think it would remove one of those basic ethos you work towards them being as independent as possible.

And can you really put a cost on a family breakdown, or something? I mean that's an intangible cost. Incalculable.

I think if it goes ahead, we will have to look what effects it will have because I think undoubtedly there is going to be full effects for him. Alternatively where he would go is a big problem because there is nothing else in Scotland compared to Camphill, and that's why I think it is important to try and stop it going ahead than anything because it is too late when it does go ahead for children like him and I think we should be proud up here that we have something to accommodate the children and adults to give them the life style they have, because I think that's what they deserve.

If you had flowers or trees which were unique to Camphill, they probably wouldn't build the road.

I do appreciate that they need a road to help the flow of traffic, and I do understand the road has to go somewhere but I just feel that this is the most vulnerable group, the group that it would impact on their lives the most... This is a special place, it's peaceful, it's

tranquil, it's safe, it doesn't want any roads or traffic or strange people coming through it, and that's part of the attraction here. I've seen the other options and know that it will impact on other people's lives somewhere and that's sad but this particular group of people they are the most vulnerable so it shouldn't even be a consideration because in the long term the price will be so high.

3.7.5 Summary

It was apparent that all parents had serious concern regarding the road and its potential on their children's well-being. The main concern centred on the impact on the environment, in particular increase in noise levels, restrictions to freedom and issues of safety. These were all projected to have negative consequences for their children, jeopardising the improvements so far achieved and inducing regression. To risk these impacts on their child and on family quality of life were for parents unacceptable.

3.8 CRSS Personnel Responses

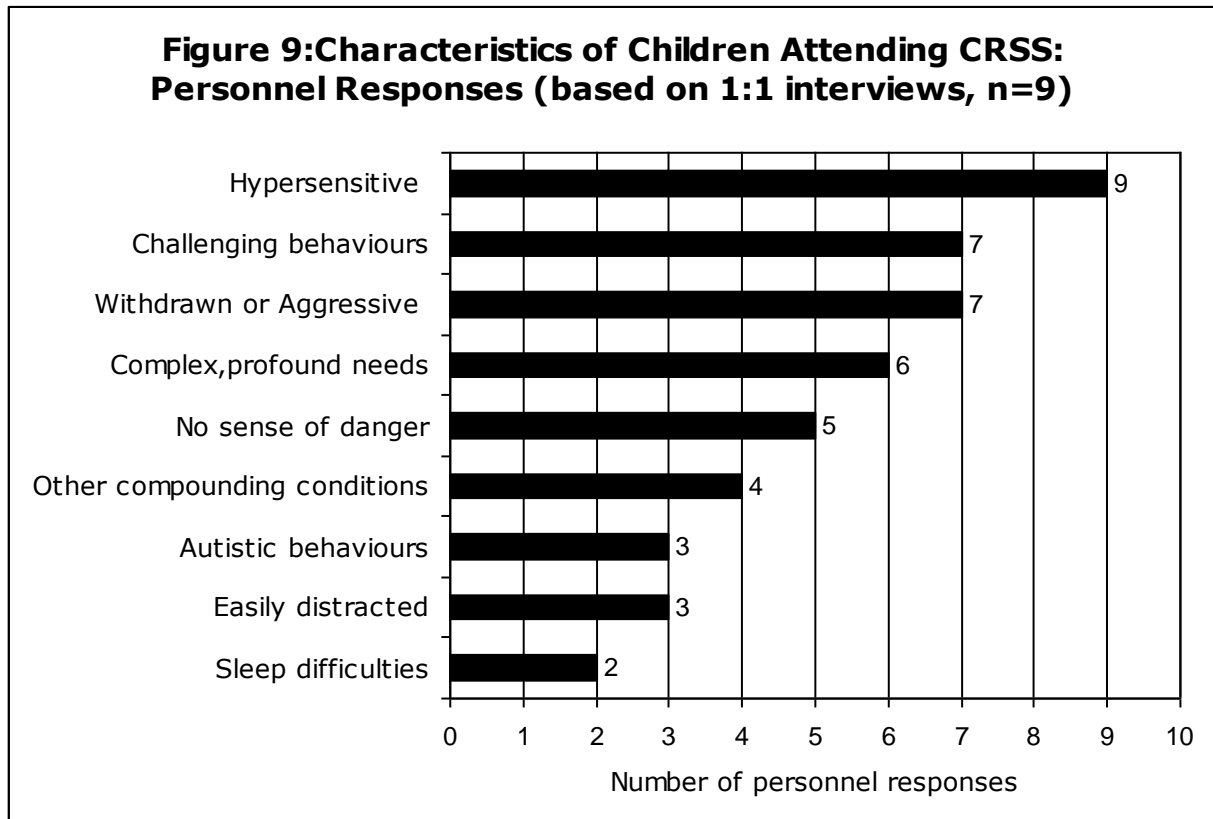
The results of interview and focus groups were consistent and therefore while analysed separately are reported together. The numerical data analysis refers only to the interview data. The personnel responses were recorded separately from parents and researcher observations, and as such are relevant in their own right, but also serve as a reliability check on perceptions about children, families and life at CRSS provided by parents and researcher observation. Although personnel focus more on programme approach and content as might be expected, the overwhelming impression is one of consistency and similarity to others sources of data about children attending CRSS. The emerging themes are addressed under the following headings:

- characteristics of children attending CRSS
- why children come to CRSS/placement at CRSS
- changes in children after a period at CRSS
- CRSS: Important aspects
- CRSS and the wider community
- CRSS and the proposed AWPR

For a summary of the focus group's analysis see Appendix 2

3.8.1 Characteristics of Children Attending CRSS

The nine interviewees and six focus group participants all had regular contact with children in a variety of circumstances within CRSS. Some spent extended periods of time with the children, for example in school or the house setting, and others more brief periods of time such as in horse-riding therapy. The data from the interviewees are summarised in Figure 9.



Personnel all highlighted the sensory hyper-sensitivity of the children, particularly to sound, but also to other sensory stimuli, such as light and vibration. These often disrupted children's behaviour in relation to normal activities and/or triggered challenging behaviours. Children were perceived as easily over-stimulated and distracted. Responses to unexpected, unwanted or over-stimulation were noted and ranged from withdrawal to aggression. These included self-abuse, physical aggression towards others, running away, throwing things and verbally abusive behaviour. Some were easily upset by the behaviour of others around them and many had difficulties in coping with changes in routine. Many children were perceived as lacking a sense of danger

and often showed a fascination with traffic and machinery. In some cases this was associated with climbing fences and sitting down on busy roads. These indications are consistent with the reports in the literature on children who show extreme behavioural disturbance.

The majority of the respondents noted that the children showed challenging behaviours of an extreme nature. Personnel commented that although many of the children had autism, other complex conditions were present in the group. It was noted that children had complex, multiple needs which were frequently extreme. Compounding conditions such as epilepsy, allergies, physical difficulties, speech problems and emotional difficulties were also highlighted. Dietary problems were also mentioned and one of those interviewed estimated at about 20% of the children in CRSS had food sensitivities. The fact that children had sleeping difficulties was also commented on.

3.8.2 Why children come to CRSS

The personnel, like the parents, state that children come to CRSS because other placements had broken down and/or were unable to meet the needs of the child. Children were seen as to “not fit” elsewhere, and CRSS was often seen as the only place that would meet a child’s needs. Again this is considered to have arisen because of the severity of the children’s behaviour and complex, multiple needs. The results are highly consistent with our knowledge about children with autism spectrum disorder and other multiple disabilities associated with learning disabilities. These results are also consistent with the commentary from parents. Again, one must conclude that the children attending CRSS represent the extreme of a continuum in terms of aberrant and disruptive behaviours, and show marked sensitivity to stimulation within their home, school and community. My visits, for example, to the group homes and kindergarten, including participating with children at mealtimes and accompanying them on walks, reinforced this view.

3.8.3 Changes in children after some time at CRSS

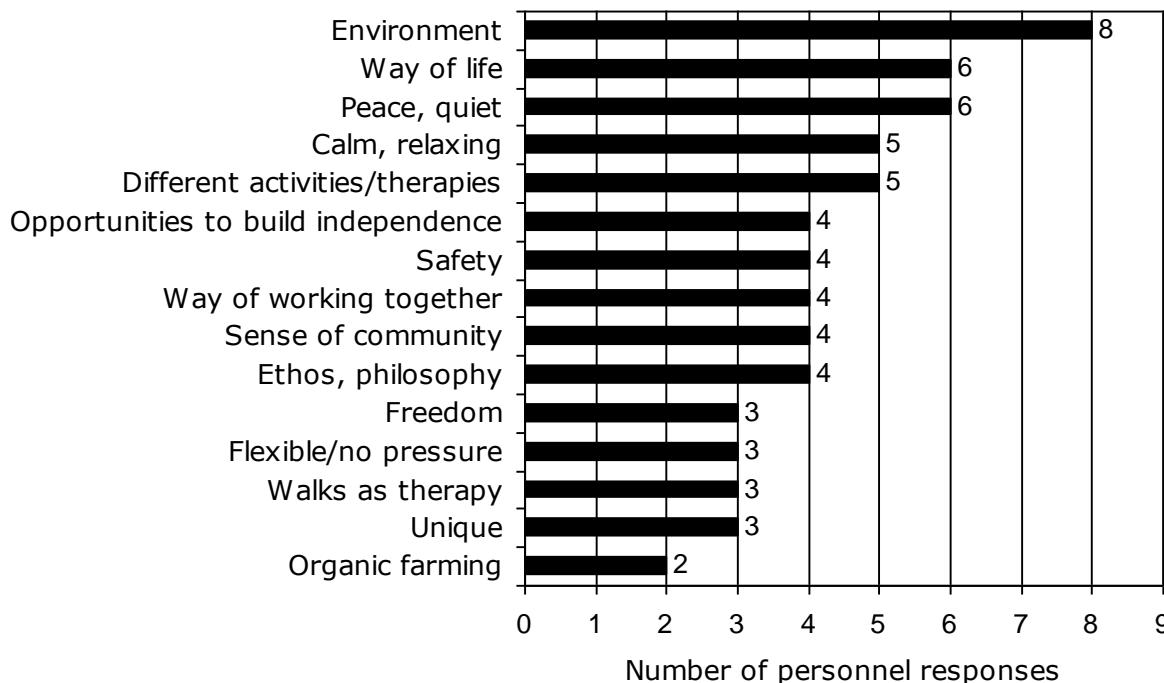
After children have been awhile in CRSS, personnel are able to provide a number of comments based on their observations and experience. It is clear that the majority of personnel noted positive changes in the children after some time at CRSS. Children seemed more content, relaxed, happier and at peace with themselves. There was also a

reduction in challenging behaviours, although one staff member noted that changes were gradual and that there were varying degrees of success. This is readily apparent from observation of the children and the reports given elsewhere in this document. Children show increased participation and ability to interact. Acquisition or improvement of skills in a number of areas were highlighted included instances of individuals starting to talk, walk, dress themselves, becoming toilet-trained, gaining independence skills (e.g. going shopping). Interviewees noted that some children slept better at night. Progress is seen as varied and to an extent dependent on the stability of the surrounding environment. Improvements were likely to be easily disrupted by changes to the environment and sensory stimulation, particularly noise. These influence behaviours and can cause regression. The personnel's observations of such regression when change occurred are supported by the literature (see Wing, 1992; Brown & Hughson, 1993). All these remarks are consistent with the parent's reports on their children after they had spent a while at CRSS.

3.8.4 CRSS: Important aspects

Figure 10 shows the numerical analysis of comments by personnel interviewees on the important aspects of CRSS.

Figure 10: Important aspects of CRSS: Personnel Responses (based on 1:1 interviews, n=9)



Personnel highlighted both the natural and built environment of CRSS, developed over some 65 years, as important elements in the therapeutic programme. The quiet and peaceful natural environment, with its safe yet open space, was perceived as offering the security, freedom and calm necessary for the children to relax and benefit from the integrated approach of CRSS which encompasses education, therapy and living situation.

Many mentioned the extensive use made of the outdoor environment of the campus with activities such as bike riding, walking, play and horse riding being used for therapeutic, educational and recreational purposes, contributing to the overall wellbeing and improvement of the children. Time outdoors within a structured but relatively free natural environment was highlighted as a vital factor for many of the children in enabling them to cope with time indoors and interaction with others. The use of the outdoor environment as a therapeutic approach and resource was considered to be possible because of the qualities of the natural environment prevailing on campus. The views of personnel on

the importance of the environment for the development and well-being of the children are corroborated by external inspecting authorities⁸

‘calm and restful environment both indoors and outdoors reduced stress and gave children the freedom to explore and investigate the materials around them.’

‘the need for outdoor play recognised, routines were flexible to support this, good use was made of the wider school campus , the peaceful countryside environment was a key factor in creating the stress free environment that some children’s complex needs required. The safe, wide open spaces allowed freedom for energetic physical activity crucial for their good health’

In addition to the natural environment, aspects of the built environment were highlighted as significant for the well-being of the children. Attention was drawn to the thoughtful use of space. Buildings have been carefully placed to facilitate independence and localisation of noise. Even so, some homes seem more suitable for certain children than others because of current proximity to outside roads. Within school buildings, kindergarten and houses the provision of micro-environments appropriate for various activities - therapy, play, exploration, solitude, socialising - are seen as important contributors to development and behaviour modification. Placement of buildings, their internal decoration, the surrounding green environment, were all thought to be conducive to child development.

The integrated and holistic nature of the programme along with its general ethos and underlying philosophy were considered by personnel to be significant elements in the CRSS approach. Respect for and acceptance of the individual, despite behavioural difficulties, emerged as a key concept. This appeared to unify and underpin all the work done with a child. This was exemplified by the highly flexible, individualised programmes of education, therapy and care developed with each child. These were implemented within an underpinning daily, weekly and seasonal routine, which personnel observed to be important in giving a secure framework which helped to reduce stress and anxiety.

⁸ Scottish Commission for the Regulation of Care report on Amber Kindergarten March 2005 p3,6

The CRSS community, where many personnel and their families live on site with the children, was identified as a further supportive element, creating a stable community into which the children could integrate. In addition, the opportunity for a life style lived at a slower pace with less social and environmental confrontation was perceived to be another contributory factor. Opportunities for building independence were also identified as significant for the development of the children. The configuration of the school campuses, their proximity to the old Deeside walkway, other Camphill communities and local amenities were considered to facilitate this.

Also mentioned as important in contributing to the well-being of the children was the availability of organic foods from farming activities on the CRSS grounds and their use within the school's community. All these items, again, are very consistent with the reports from the parents, through interview and focus groups.

Through on-going contact with parents, personnel noted that parents commented on changes in their children when they are at home, such as being more relaxed, easy to be with and sleeping better. CRSS also offers support and workshops to parents, covering a wide variety of themes relevant to their child.

3.8.5 CRSS and the wider community

Comments in relation to the wider community were varied and different personnel tended to mention different characteristics, possibly because they were in positions that brought them into particular and specific contact with the outside community. Overall there was a sense that CRSS has an increasing relationship with the wider community. That perception of the personnel is evidenced by the following:

- re-integration of some children eventually within mainstream schools and/or within home
- provision of play/assessment sessions for local primary school children with challenging behaviours and support sessions for their parents through a the multi-agency partnership project with local primary school and healthcare services
- the development of inclusive services such as the kindergarten, for 3-7 year old children with and without special needs

- provision of employment and contracting opportunities for local people and businesses
- open days attended by local community
- interaction of older pupils with wider locality through visits to Aberdeen
- employment of former students in the local area

Personnel also highlighted that relationships with the academic community have been forged through the BA in Curative Education delivered in partnership with the University of Aberdeen. This practice-based course draws on an international student base and is recognised as professional qualification for residential care work by the Scottish Social Services Council.

Accreditation of CRSS by the National Autistic Society was seen as evidence of CRSS' expertise and quality of provision for children with ASD. Exceptionally positive reports by inspecting authorities, Scottish Care Commission and Her Majesty's Inspectorate of Education (HMIE), were considered to be further indications of the validity of the CRSS approach and that it is a valued contributor in the range of services for children with complex needs. It is interesting that a number of factors highlighted by personnel as significant for the well-being and development of the children such as the quality of the environment, were also reflected in the above reports.

Further afield, CRSS and its programme is regarded as making a positive and necessary contribution to the field of disability. Commentary in response to the Save Camphill Campaign from eminent international experts in the field, all of whom have knowledge of CRSS, illustrates this.

3.8.6 CRSS and the proposed AWPR

Personnel were all opposed to the proposed Murtle option for the AWPR. They considered it would have detrimental effects, both during construction and operation, on the children attending CRSS and on their integrated programme. Specific concerns were highlighted.

Destruction of the peaceful environment through substantial increase in noise, vibration and activity arising from the road, resulting in raised levels of overall stimulation, was a

major concern. Currently dealing on a daily basis with the particular sensitivities of the children at CRSS, including inability to filter sensory stimuli, negative reactions to change, hypersensitivity to noise, vibration, and visual stimuli, personnel were aware of the likelihood of deterioration in behaviours, with increased unpredictability and decreased ability to learn. Destruction of the natural environment was also seen to run counter to the ethos of Camphill which has been concerned with preserving and enhancing the natural environment for over 65 year.

An increase in safety issues was also highlighted. The presence of traffic nearby allied to some children's abnormal fascination with this and the tendency for unpredictable, sudden and erratic behaviour, raised concerns over difficulties in preventing some children exposing themselves to/accessing the dangers of the road. These issues raised concerns with regards to:

- the imposition of increased necessary safety measures
- the restricted use of the outdoor environment.

The projected need for greater 'containment', with effort being expended by personnel to keep children from gravitating towards the road, was deemed detrimental to the children's development, as was the visual and perceptual intrusion of any perimeter fencing required for safety reasons. It was pointed out that such safety measures represented a backwards step in the approach to children with special needs and ran counter to CRSS philosophy of encouraging maximum freedom and independence within a safe environment. Further, it was difficult to reconcile physical restrictions such a perimeter fence with the CRSS ethos and with current trends towards the removal of barriers to the inclusion of special needs children within the wider community.

There were also concerns about restricted use of the outdoor environment, both on and off campus, as a therapeutic resource primarily as a result of safety and noise issues. Currently children have freedom within the campus, and to access other Camphill communities and the local community via the old Deeside walkway, with or without supervision, as is appropriate for their degree of independence. The closeness of the new road would necessarily mean some facilities and activities would be off limits to children. Such a reduction on current freedoms was considered to have negative consequences for building independence and for therapeutic practices.

Personnel noted that the foregoing impacts would all have negative consequences for the children, causing deterioration in behaviour and interfering with positive development and progress. The children's disturbance would, it was perceived, increase pressure on personnel. This in turn would have a concomitant negative effect on the children resulting in an escalating spiral of impact. I concur with this view having worked for a considerable period with children and adults with disabilities. Change and increased ambient stimulation can result in behaviour changes, which increase the stress levels on staff working with such children.

4. CONCLUSIONS

4.1 Overview of conclusions

This section will summarise the overarching conclusions from the study.

The study reported was designed to understand the effects of the proposed Murtle option for the AWPR on the children attending CRSS and their families from the perspective of quality of life and the practices of CRSS. It should be noted that the conclusions regarding the impact of the AWPR on CRSS relate primarily to the Murtle option. However, the report still has implications for the Milltimber Brae option of the AWPR near to the CRSS Camphill Estate campus, since parents and children from both sites were included in the study. The conclusions regarding children's behaviours, effect on families, improvement in children and family quality of life and the practices of CRSS are relevant for both campuses.

The children attending CRSS, both Murtle and Camphill campuses, are a highly vulnerable sub-group within the special needs population. They are characterised by a variety of complex diagnoses and complex additional support needs. In addition some of them have multiple diagnoses, such as Down syndrome and Autism Spectrum Disorder. All show a range of emotional and behavioural challenges and the majority have learning disabilities. These characteristics are clearly recognised in the classical diagnostic manual referred to as *DSM-IV-TR*. Unfortunately, it has not been always been acknowledged that children who have learning disabilities can also have classical behavioural or mental health challenges. In the case of autism, behavioural concomitants have been clearly documented (see Wing 1993; Frith 2003), but the idea that multiple diagnosis can occur, for example, Down syndrome with Autism, or/and depression or psychosis has not been so readily accepted. This is now no longer the case. The recent Diagnostic Manual-Intellectual Disability⁹ clearly recognises this and provides detail on the expectations which can occur when learning disability (intellectual disability) is also present (see Fletcher et al, 2007). The diagnoses of children at CRSS who were included in this study include Down syndrome, Fragile X, Autism Spectrum Disorder, Pallister-Killian syndrome, Foetal Alcohol syndrome, CHARGE syndrome and

⁹ The manual, although US based, has several authors from Scotland and England and has internationally recognised authors as its authority from a variety of disciplines.

Rett syndrome. The child profiles are complex with multiple diagnoses, sometimes of a clear biological nature as in epilepsy; double or triple diagnoses e.g. Down syndrome and ASD, and Attention-Deficit/Hyperactive disorder. As can be seen from the sample data sleep disorders, aggressive and tantrum behaviour frequently occurs in these children along with motor and perceptual disturbances. For the most part these children represent the grossly behaviourally disturbed end of the continuum. This is why their families are desperate for help and find it essential to have a safe, supportive and caring environment for their children.

The effect of these children with their extreme difficulties and behavioural challenges on their families is massive. This has been documented in the results section in some detail. Normal family functioning was profoundly disrupted with restrictions and negative impacts in many areas, including family relationships, social inclusion, work/career and health. The literature also bears this out (e.g. 2006 Special Issue, Family Quality of Life, Journal of Policy and Practice in Intellectual Disabilities). It is for these reasons that CRSS is required. CRSS preserves an environment which enables children to improve, and at the same time critically helps families to re-establish as normally functioning units. Children can gradually reintegrate more successfully in home and in the wider community.

It has taken many years to build up the programmes and facilities at CRSS, both carefully and consistently, with developing knowledge and experience. The approaches used are all believed to be relevant to children with high levels of disturbance, and individually these approaches have been described in Camphill documents. They are also noted in the clinical and research literatures. It is logical to predict that the integration of all these aspects, such as practiced at CRSS, would likely have a greater positive impact on such children. Research-wise this combination is difficult to assess, but the results of the current study suggest that many children (certainly the great majority of those sampled), and probably most, are observed to have made considerable, though varied, progress. Transgression of any of these aspects from outside influences, such as the AWPR, would be likely to threaten the ability of the CRSS community to successfully deliver its service and to develop in the future. It is clear that CRSS is a resource for a highly vulnerable group of children, with additional support needs, and their families, providing a service in line with many modern concepts

of quality of life. As such it should be allowed to continue its development and its contribution to the spectrum of provision for such children now and in the future, unimpeded by threats to its practice and ethos.

It is my view that Camphill is an ongoing “experimental” model and any damage to its holistic approach is likely to impede the generation of knowledge and experience, which is desperately needed as society encounters greater numbers of children with complex and multiple additional support needs.

4.2 Specific conclusions

This section of the report details a range of specific conclusions arising from the data from the current and previous interim reports.

Diagnosis

1. Children attending CRSS, both day and residential pupils, have complex and multiple diagnoses which have extreme physical, learning, emotional/social/behavioural components.
2. With regards to diagnosis they are a mixed diagnostic group dominated by children with learning disabilities and autism spectrum disorder. A few have Asperger’s syndrome.
3. Symptomatology includes a history of anxiety, sleep problems, epilepsy and allergies.
4. Many have functional difficulties related to speech and language, motor skills, and sensory perception. Multiple sensory hypersensitivities are common, causing abnormal behaviour and inhibiting moderation of behavioural responses in a wide variety of situations. Many are very sensitive to environmental changes.
5. All can be described as children with severe emotional and behavioural challenges.
6. All children present extreme and multiple challenges
7. The literature confirms and supports the vulnerability of such children in terms of their unpredictability in behaviour and their aberrant responses to the environment, including social and community situations. The results indicate that they represent an extreme in terms of their range of learning disabilities and emotional challenges.

8. It would be reasonable to regard these children as a highly vulnerable sub-group at the extreme end of the continuum of additional support needs.

Behaviour of child prior to CRSS

9. Children's behaviour, prior to attending CRSS, was extremely disruptive, unpredictable and often uncontrollable.
10. All children had multiple behavioural challenges, which were diverse and generally extreme in degree.
11. The challenges presented by the behaviours of these children could not be met in a variety of settings including the local community, school environments, or in the home.

Impact of child on families prior to CRSS

12. Children with such complex diagnosis and challenging behaviours had an extreme impact on family members and family life, causing massive changes in lifestyle and always leading to disruption and restrictions in normal family life.
13. In some cases the behaviour has led families to the verge of breakdown. Some families had broken down.
14. Quality of life for children and their families was seriously compromised.

Changes in child since starting CRSS

15. Parents and personnel recognise major and minor positive changes in children, often after a brief residential or day placement at CRSS, including the nursery.
16. When children return home, parents commonly find the child more manageable and able to be accepted within the family, so that a more normal and regular family routine could be established.
17. Parents and personnel note a wide range of progress in children and reduction of aberrant behaviours.
18. Despite this many of the children still remain very disturbed and vulnerable to minor change and cannot adapt to unstable environments.

Changes in family life since child started CRSS

19. As a result of the child's placement at CRSS families experience an overall improvement in their quality of life. Restrictions on family activities are alleviated

and normalisation of family functioning begins to occur and often becomes established.

20. Siblings benefit with opportunities to study effectively at home and establish a normal social and community life.
21. The sense of social isolation and exclusion for family members is reduced
22. Several marriages have been stabilised, and the family unit preserved once the child was admitted to CRSS and therapeutic regimes had been established.

Importance of CRSS: Parents' perceptions

23. The quality of the quiet and stable environment, the integrated and inclusive approach and quality of the personnel are the main features which parents value and consider key in their child's quality of life and improvement.

Quality of the environment

24. The quality of both built and natural environment at CRSS/Murtle estate, characterised by peace and tranquillity with minimal unwanted/intrusive sensory stimulation appear to be a significant factor in enabling children to relax and benefit from the programme.
25. The low ambient noise outdoors is essentially that of the countryside. Over night the prevailing silence is exceptional. This encourages children who have sleep disturbance, and/or are easily agitated and affected by changes in ambient noise, to become rested and then to stabilise and interact with their surrounding environment in a more appropriate manner.
26. The extensive safe, open outdoor environment, with low ambient noise and minimal intrusion, gives children maximum freedom and opportunities for building independence. It also enables them to cope with social interaction and the indoor environment.
27. The use of the outdoor environment as a therapeutic, educational and recreational resource is key to the approach at CRSS, and is used extensively on a daily basis.

Inclusive and integrated approach

28. The programme is an holistic one, consistent with modern practices in terms of quality of life, both for the children and families.

29. Parents who have managed to get their child into CRSS regard the school environment, which includes Murtle Estate, as an oasis of care, understanding and support
30. Continuity between education, therapy and living situation provide opportunities to practice an inclusive and integrated approach, to the benefit of the children and their families. Life and social skills are enhanced
31. The availability of medical services and wide range of therapies on-site further strengthen the delivery of an integrated service.
32. Respect for each child as an individual is an underlying principle which is practised throughout CRSS and which parents perceive as critical for their child's needs to be met.
33. Highly individualised flexible programmes are developed for each child and are implemented within a structured and sensitive routine.

Quality of CRSS personnel

34. Parents appreciate the understanding and dedication of personnel, including the availability of one-to-one skilled support. They recognise these as essential components of the integrated care/education/therapy programme.
35. Continuity of personnel and consistency of approach coming from a shared value base is important in building of child and parental trust.
36. Personnel are highly skilled and show a high level of understanding and commitment to children and their families.

CRSS and the wider community

37. CRSS is integrated with the local communities in a variety of ways, thus normalising the environment as far as possible. This includes an integrated nursery.
38. The proximity and accessibility of other Camphill communities and the local community via the old Deeside walkway further enhances integration.
39. The availability of shop, bakery and store, plus general practitioner and allied health services within the Camphill communities are welcomed and extensively used by the local community. These are areas where interaction of children and adults with special needs and the general public takes place. This is valuable for inclusion within a still sheltered environment.

5. KEY RECOMMENDATIONS

Three major recommendations are put forward.

1. It is extremely important that the Scottish Government and local councils as well as disability, social work, health and educational services recognise that CRSS is an exceptional resource, which should be supported, protected and advocated as a place where children with complex and multiple needs, including learning disabilities, who show extremely challenging behaviour, can gain support and assistance.
2. It is also critical to recognise that these services provide respite for families which enable many of them to re-stabilise and become functional again. This is in the interests of both the children and their families. It is in the interests of the government, as well as the range of services, that these positive effects on children and families can occur without disruption.
3. Lastly, the evidence indicates that the children attending CRSS represent an extreme sample of people with disabilities who are extremely sensitive to change and disruption, and the types of environment that precipitate or help to maintain aberrant behaviours should be avoided. The risks of developing the AWPR as proposed, or in any similar close proximity, should be avoided as the risks to children and families are extremely high given the nature of the children's disabilities and needs.

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Appendix 1

Summary of focus group results:

Parents with non special needs children attending CRSS Amber Kindergarten (n=2)

Other programmes:

- Noisy
- Rowdy, rushing around
- Not enough caregivers for children

Why Camphill?

- Child sensitive
- Need for extra care, attention
- Might be bullied elsewhere
- Organic food
- Looked around, my preferred choice

Stated likes about CRSS kindergarten programme

- Children interact with each other
- Son doesn't look at child with special needs differently
- Non special needs child has to fit in, not vice versa
- Helped child to develop as an individual
- Responded to care
- More confident
- Really settled and happy
- Interacting, making friends
- Adult to child ratio good
- More individual attention
- Ambience, atmosphere
- People are soft spoken
- Very nurturing and caring
- Feel safe and secure
- Holistic approach
- Activities and the strategies used for activities
 - Focus on a few things at a time e.g. 2 or 3 colour
 - Beginning to end e.g. wheat growing to bread making
- Outdoor activity
- Aesthetics of building
- Well equipped e.g. toys wooden, hand crafted not plastic
- Health conscious
- Celebrate festivals
- Parents made to feel part of kindergarten
- Supportive of whole family
- Get to meet, know other parents

Comments about Camphill

- Loving acceptance of child as an individual
- Philosophy
- Individual special & specific needs met at Camphill
- Friendly
- Unique (e.g. like an oasis)

- Beautiful environment
- Peaceful relaxing
- Safe
- Has working farm
- Organic food
- Take health seriously
- Access to city

Camphill and wider community

- Camphill not isolated
- Camphill important part of larger, local community
- People shop at Camphill (e.g. bakery, coffee shop, organic food)
- People access medical services – expertise
- People walk around the grounds e.g. to farm
- Camphill residents go to town and are known

Appendix 2

Summary of focus group results: CRSS personnel

Children come to Camphill because...

- Other situations breakdown
- Does not fit in anywhere else
- Seen as the only one would meet needs

The children that come to Camphill...

- Are easily upset by behaviour of others
- React to in ways that differ (e.g. withdrawn, hard to understand, fascinations)
- Easily over-stimulated / distracted
- Find it hard to cope
- Have challenging behaviours (e.g. aggressive, screaming, verbally abusive)
- Have more complex needs
- Compared to before, now more challenging child
- Have autism
- Have other conditions (e.g. ADHD, epilepsy, physical disorder, does not speak, emotional difficulties, special diet)
- Sensitivities (to noise, light, food – est. 20% have food sensitivities)
- Have sleep difficulties
- Not aware of danger (e.g. traffic, fascination with machinery, climbs fences, sits on roads)

Changes noticed in child...

- Reduced challenging behaviours
- Improved (e.g. increased participation, more at peace)
- Improved skills (e.g. start talking, walking, dressing self, shopping, toilet trained)
- Sleep better
- More relaxed
- Happier
- Varying degrees of success

Family Relations

- They fight for access
- Parenting workshops offered (e.g. partnership practice group)
- Parents comment on change (e.g. child more relaxed at home and easier to be with / sleeps better)

Important aspects of Camphill...

- Ethos, Philosophy (e.g. respect, holistic approach)
- Natural environment
- Peace, quiet
- Calm, relaxing
- Freedom
- Safety
- The way in which we work together
- Different activities & therapies (e.g. outdoor activities, bike riding, walking, festivals)

- Organic farming
- Unique (e.g. history, population)
- Sense of community (e.g. commitment to each other)
- Lifestyle, way of life
- Environment (e.g. use of space, placement of buildings, atmosphere of light, site relative to others, decor)

What Camphill has to offer...

- Inclusive kindergarten
- Fun place for children
- Takes part in seasonal changes
- Welcoming environment
- Walks through nature

The approach used at Camphill...

- No pressure
- Acceptance of individuals
- Adapts to environment & activities (e.g. clay, song & dance)
- Walks as therapeutic approach
- Routine is important
- Flexible
- Opportunities to build independence
- Walks as therapeutic approach

Relationship with wider community...

- Partnership project with primary school (regular attendance by some pupils from local school)
- Inspected by authorities
- Increased bureaucracy from outside
- Contracting firms have been accommodating (e.g. precautions slow them down)
- Students from BACE course
- Recognized for contribution to field of disability (e.g. National Autistic Society)
- Easy access to town
- Go to town shopping
- Former students employed in town

Road proposal...

- Opposed to road (e.g. noise, traffic, impact on staff, impact on children, safety, stress, pollution)

Appendix 3

MAP 1: AWPR Murtle option





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