

Extract from

GOOD LIVES GOOD CARE

*A report by the UnitingCare Qld
Centre for Social Justice*

*In partnership with the Family Advisory Committee
of the Shared Care and Family Support Service (LCCQ)*

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During 2005, the then Family Advisory Committee (FAC) of SCAFS approached the Director of the UnitingCare Centre for Social Justice (CSJ) to undertake research around the roles and concerns of Shared Care Providers. The CSJ focuses on promoting social justice considerations and outcomes in human service policy and practice across Queensland, and specifically within UnitingCare Queensland human services.

With the closure of institutions, support for individuals with disabilities has, as much as possible, been located within supported accommodation services in local communities. This priority has also been established for children with disabilities, and, where children with disabilities can no longer live with their birth families, human services have received funding to support them to live in alternative family environments.

SCAFS, or the W.R. Black Shared Care and Family Support Service, is one of the support services of UnitingCare Queensland. SCAFS provides family-based supports to children with disabilities who no longer live with their birth families (Shared Care), and to families whose children with disabilities continue to live at

home (Family Support). Children in Shared Care arrangements live with families, or Shared Care Providers, and each child is supported through SCAFS by a team that includes direct support workers and a Key Worker.

The Scope of the Project

The purpose and scope of the study was agreed upon by both the FAC and CSJ. It involved answering the research question, which was established by the FAC and CSJ as being:

What would it take for shared care/host families to support children:

- ***To flourish;***
- ***To experience a broad array of life's options;***
- ***To be loved and to love; and***
- ***To experience a stable family base?***

The research would therefore focus on identifying what supports are most needed by families so that the children and young people with disabilities are more likely to lead good lives.

It was also determined that the nature of the research project needed to be one of social justice in relation to children and young people with disabilities (a group of people who are amongst the most marginalised and vulnerable in society), and that the project would be one of enquiry, not of service evaluation. Additionally, the project would aim to address the research question within the context of discussions with the families and young people/children identified by SCAFS, as well as staff, and would also include a review of the relevant literature.

Frameworks Underpinning the Project

The research process was focused on the perspectives and experiences of the families and young people being supported, and acknowledged that children with disabilities require support, not only in disability-specific ways, but in ways that acknowledge the full range of typical human needs. The study also acknowledged

that services need to provide support to people with disabilities in ways that enhance their standing and acceptance in the community.

Several important frameworks underpinned the project.

UnitingCare Queensland and Lifeline Community Care Queensland values and commitments related to vulnerable individuals: These values highlight the need for UnitingCare and Lifeline Community Care services to work within the Christian vision of the Uniting Church. The values of Lifeline Community Care Queensland include the concepts of justice, compassion, a welcoming spirit, stewardship, community, and wellbeing.

Model Coherency: The need for services to address the most fundamental, urgent and real needs of service users through using the most relevant and potent strategies.

Ordinary (Good) Life: The Ordinary Life framework is a valuable tool from which services can better understand the needs of people who live with impairments. Ordinary Life implies having access to, and being supported to attain, the richness of daily life that people without disabilities of similar age, sex and culture experience in their everyday lives.

Person-centredness: Person-centredness is an approach that honours the unique characteristics, needs, hopes and vulnerabilities of each individual, and works to keep people, and their needs, as the focus of the service and workers' efforts.

Right Relationship: Right relationship between a service and its users requires the development of an organisational ethic that promotes equal partnership, and that respects and enhances the humanity, autonomy and dignity of service users. Right relationship requires services to reject dominance as their *modus operandi*, and invites them to relate authentically 'with' people, rather than talking 'down to' or 'at' them.

Partnership: Partnership between service users and the service embodies the quality of 'witness'. Witness involves finding common ground, identifying overlapping goals, and facilitating the aims of each party. From a family's perspective, a highly

beneficial partnership with a service requires the service's recognition of parental expertise and the individuality of each family.

'Natural' Authority of Families: This concept acknowledges that parents, by nature of their roles, are the ones who have primary authority and influence in the lives of children and young people. As a result of this 'natural' authority, commitment and expertise, it is appropriate for services to value, facilitate and protect the rights of families to decide what they need from services.

Research Methodology

The Research Team consisted of:

- ✚ Mr Greg Mackay, Director of the CSJ;
- ✚ Ms Liz Upham, Consultant to the CSJ;
- ✚ Ms Caitlin Whiteman, Research Assistant (CSJ);
- ✚ From November, 2005, Ms Adrienne McGhee, Senior Policy Officer (CSJ).

A Reference Committee was established to ensure that the project was designed and conducted in ways appropriate to both the FAC and CSJ. The Committee was comprised of the Research Team and:

- ✚ Ms Robyn Jackson, a member of FAC;
- ✚ Rev Bob Harriman, Facilitator of FAC;

In order to listen to, understand and provide a voice for families within their unique situations, the Reference Committee chose to use a qualitative methodology for the project. The qualitative research methods selected for the project were:

- ✚ A literature review;
- ✚ Focus groups with families;
- ✚ Semi-structured interviews with families; and
- ✚ Semi-structured interviews with SCAFS staff.

Interviews and focus groups were audio taped and later transcribed. A second researcher was also present at the interviews and focus groups and took notes.

These methods were incorporated into the overall schedule for the project, which incorporated the following activities:

✚ **EVENT: Introduction to the research.**

This event enabled families to hear about the research, have contact with other families, have opportunities to celebrate and lament their experiences, discuss ideas and issues, and be invited to take part in the research activities.

✚ **RESEARCH: Literature and environmental reviews.**

A literature review provided the research team with a good understanding of the issues, relevant Queensland legislation and policies, new ideas, supports that have worked well elsewhere, and supports that have not worked well.

✚ **RESEARCH: Focus Groups.**

Eighteen people were interviewed in four groups. Researchers used one key question and four prompt questions (as derived from the Introductory Event) to elicit responses. Families' stories, opinions and attitudes revealed considerable depth and detail about their experiences as Shared Care Providers.

✚ **RESEARCH: Family interviews.**

Six families with contrasting experiences were interviewed individually. A list of themes that had emerged from the research prior to that was presented to families; they were invited to select and discuss themes that were important to them. This process also provided an opportunity for families to discuss issues that they did not want to address in group situations.

✚ **RESEARCH: Staff Interviews.**

Nine staff members from SCAFS were interviewed for the purpose of enriching the data obtained from families (including identifying useful ideas) and comparing staff views on what supports are most effective.

✚ **EVENT: Return event for all families.**

The Return Event was an opportunity to maintain interest, demonstrate accountability, and gather reactions to, and ideas about, the findings obtained so far.

✚ RESEARCH: **Transcription, Analysis, and Report Writing.**

Notes and transcripts from the research process were analysed and themed using NVivo (a computer program used for the analysis of qualitative data).

✚ EVENT: **Launch of the Report.**

The research findings have been compiled as a report. The purpose of the report launch is to demonstrate accountability to the families, to encourage follow-up on the issues, and to make a statement about the importance of the project within the context of young people and children with disabilities having opportunities to live good lives.

A number of assumptions were made when undertaking the research aspects of the project. These assumptions include the following:

- ✚ That families are the best people to answer the research question;
- ✚ That asking the same questions of staff helps to clarify what each group involved with the children are experiencing, thinking and feeling;
and
- ✚ That a participative and developmental approach will increase the likelihood of internalisation of the findings by the service.

Challenges

One of the major challenges of the research involved ensuring participants remained focused on the purpose and scope of the project rather than reviewing the performance of the service.

It became apparent that families needed an opportunity to come together to chat and/or debrief about their experiences with SCAFS. This need required extra time and preparation that was incorporated into the overall plan for the project.

On occasion, the sharing of information and experiences resulted in family members raising their points of dissatisfaction; in such instances it was relevant to remind participants that it was not the purpose of the project to generate discontentment with the service but to identify the support they need to bring about good lives for the children they support.

Ethical Considerations

The contextualist, or holistic, stance is believed to be the most appropriate ethical approach for this study. This stance is used when information is sought within specific contexts, and when the people involved can provide the richest source of information within that context. Practical considerations which flow from this stance include: informed consent; ensuring confidentiality; avoidance of harm; and reciprocity. All of these aspects of the contextualist approach were addressed appropriately within the project.

ESTABLISHING A VISION FOR CHILDREN WITH DISABILITIES

The People and their Experiences of Disability

In order to understand and consequently meet people's needs, it is important to know who they are in relation to their experiences. This section of the report acknowledges the common humanity of both children and their families by looking at the vulnerabilities often experienced as a result of disability, and the exclusion that accompanies it.

A number of situations are often experienced by the children who have disabilities; it is therefore likely that these experiences are common to the children and young people supported within SCASFS families. The fact that these young people have been separated from their birth family is one of the more obvious experiences of vulnerability. Isolation, loneliness and rejection within social relationships are other commonly reported experiences for children with disabilities. Additionally, they are often cut off from typical activities and ordinary childhood experiences. These limitations may occur because children with disabilities can be overprotected, under-challenged, highly medicalised, discouraged from dreaming about the future, experience communication difficulties, and are often perceived negatively. Overall, while not all children with disabilities experience all, or any of the above-mentioned hurts, they are much less likely than a child without disabilities to have a typical childhood.

The experiences of families who care for a child with a disability are often similar. Parents who provide support for children with a disability live lives that

are frequently not ordinary, and may be filled with additional stressors. In many cases, extra support is required to meet these challenges and to sustain a functional and happy home life for the family. For instance, parents often take on an additional, and often considerable, financial responsibility when caring for a child with a disability. They frequently experience difficulties with service providers trying to ensure that their most urgent and important needs are met. They encounter barriers in obtaining information they need, and often feel exhausted, both physically and emotionally. Also, families often experience increasing isolation and exclusion from people and society who are unable or unwilling to make adaptations for a child with a disability.

In conclusion, it is vitally important for services to understand the impact of these experiences on the families who care for a child with a disability. In order to provide a child with a stable and loving family environment, and to create and maintain supports that promote ordinary life, services need to know the people they serve well, be highly conscious of the vulnerabilities experienced by families, and do all that they can to support and assist them to counteract the negative effects of these situations.

What do children with disabilities need to have good lives?

Clarity of purpose, based on deep insight into the people being served, is essential if the organisation is to provide services that address their most potent and relevant needs, and provide the greatest possible benefit. This project adopted the concept of ordinary life, or good life, as a valuable tool for constructing an overall vision for children with disabilities. Family is seen as being the primary vehicle for enacting a good life for a child with a disability.

Family living typically generates multiple opportunities for children with disabilities to experience the richness of daily life. Similarly, families provide the basic elements of good care required by all children, including: love; a warm, safe and nurturing environment; stability; belonging; the meeting of basic needs; making decisions and choices; opportunities to try new things; encouragement of interests; routine and appropriate discipline; understanding rights and responsibilities; creating dreams for the future; learning new skills; planning for the child's future; involvement in family, school and community life; support; and opportunities to meet people and build relationships. When all of

these elements of good living are part of a child's daily experience, it is more likely that a child will experience the benefits of a typical life. It is therefore vital that the family in which children are living is supported by services to meet these needs at every opportunity.

RESEARCH FINDINGS

It is evident that the experiences of the SCASF families parallel much of the literature in this area. The framework for the discussion of the findings is taken from Groze's (1996) categorisation of the types of support needed by families who adopt a child with special needs. The main categories of support identified in Groze's work are: **Emotional Support**, **Informational Support** and **Practical Support**.

Emotional Support

Emotional support addresses the emotional needs of families caring for a child or young person with a disability and the first section of the findings discusses these needs. Families caring for an individual with a disability identified numerous sources of emotional strain specific to their situation. The research findings highlighted the importance of emotional support in helping to validate parents' experiences and concerns, relieve feelings of isolation, and provide safe and non-judgmental ways to release frustrations. There was a strong need for parents to feel they could talk about their experiences with someone who understood what their experience was like without being judged or being told what to do. Supportive friend and family relationships were important to families, and while some families were wary of approaching SCASF for this type of support because of concerns around neutrality and fear of being judged, others found that Key Workers who were skilled in this area were highly supportive.

Informational Support

Informational Support outlines the types of information families need in order to provide better care to children with disabilities. Informational support was considered to be vital to SCASF families and the topic was discussed often during the sessions. Research also validates the fact that information is typically considered by families to be one of the most valuable supports that services can provide. SCASF families believed that good information enables

them to provide the best possible life for children with disabilities; it also helps to alleviate emotional distress they experience in their roles as Shared Care Providers.

The findings outlined several informational needs that families have. Families stated that information provided by the service needs to be relevant, comprehensible and accurate. They also addressed the need for the service to be more proactive in ensuring that families have the information they need - some families are less skilled and persistent than others in obtaining information, and require considerably more assistance. Families also identified the need for more information in several other vital areas such as: the child and his or her disability; relevant resources, services, and support groups; how funding worked; remuneration; the service and its policies; and workers' roles and responsibilities. Families determined that the informational needs of families would have to be met on a family-by-family basis.

Learning is also another important aspect of the informational support required by families. Families provided considerable feedback on the area of formal training, stating that they need training that is flexibly delivered and is grounded in practical experience, not in academia. It needs to be based on an understanding of the type and level of skills needed by each family. One area of learning that families highly valued was that of having opportunities to learn from each other.

Practical Support

Practical Support discusses the worker and service practices and characteristics that families identify as contributing to a good life for a child or young person with a disability. The issue of practical support generated substantial discussion and identified many needs families have.

The literature emphasises the critical nature of worker support to families and suggests that the Key Worker model (which is employed by SCASF) is generally an excellent way for services to support families. Families also agreed that Key Workers were potentially, but not automatically, highly supportive. They also identified that there was considerable variance in the effectiveness of Key Workers. The personal characteristics of Key Workers were seen to be very important to families; in particular, they need to have a genuine interest in the

child, and be flexible, fair, equitable, consistent, responsive, dedicated, trustworthy, respectful and well trained. Families particularly wanted to work in partnership with Key Workers, the importance of which is also highlighted in the literature. Additionally, families were very aware of the important contribution of support workers and considered that the most important quality for the worker to have was that of being able to work well with the child and establish 'right relationship' with him or her. Families also identified the need for workers to be appropriately trained. However, they also highlighted the very transient nature of support workers, a finding reiterated in the literature; they believed that increased support from the organisation could impact positively on support worker retention.

Access to respite was also considered important by families, and this finding is also validated in the literature. However, parents were often anxious about the quality of the respite experience for the child: it was important for families to have adequate preparation prior to the respite experience, to know that the child would be in a safe environment, and to be assured that respite families themselves were not overloaded. Two approaches to respite were also considered to be highly valuable to families: that Shared Care families and Respite families had a team approach to providing support for the child, and that respite arrangements would be person-centred, i.e. suited to the child's characteristics and personal preferences.

Other practical supports identified throughout the literature and needed by SCAFS families include: the provision of material resources such as home modifications; equitable government funding arrangements; working in partnership with the service regarding funding; adequacy, transparency and equity of remuneration; and appropriate and reliable emergency support.

Other Supports

Supports unrelated to Groze's (1996) framework were also identified by families as being useful. For instance, advocacy for the child was considered to be important by families, and parents often found themselves engaged in advocacy-related activities for the children they cared for. Several families talked about the potential benefit of having citizen advocates in the lives of children, and believed that an appropriate advocate would need to be independent, unpaid, focused on the young person/child, and free of conflicting

interests. Some parents also highlighted the benefits of having positive mentors in the lives of children. Finally, families talked about the children's and young people's need for friends and relationships, and the need for the service to facilitate friendships, and to address issues of contact according to each child's specific needs, not according to organisational policy.