Supporting Families

Family well-being and children with disabilities

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Acknowledgements

This report is the summary document of the efforts of many people. We trust their efforts and commitment to this group of families will be well rewarded by considered attention to the findings in this report. This project however could not have been completed without the participation of the families and their willingness to fill in questionnaires, take part in interviews and follow up with more questionnaires. Our thanks go to these families and particularly the primary parent-carers who took part in the interviews. We wish them well in their family lives as they continue to construct, implement and maintain their everyday family routines and provide ongoing support to their young children with disabilities.

There were numerous people who by their enthusiasm and commitment ensured that this project reached a successful conclusion. Many government and non-government service agencies went out of their way to assist in recruiting families and to participate in focus groups. For confidentiality reasons, these agencies will not be named here, but we thank them for their contribution and continued commitment to supporting families.

This report details the development, implementation and findings of the Supporting Families Project. At the end of each section there is a summary section, *Findings at a Glance*. The *Conclusion* draws together and summarizes the material presented in the earlier sections. We trust the findings from this research and development project will be given considered attention.

Background

Contents

Introduction

Around Australia policy directives and service agencies are concerned with finding effective and efficient ways to encourage families with children with disabilities to continue caring for their children at home. To investigate the factors influencing out-of-home placement in 1995-1996 the Community Support and Respite Project funded by the then Commonwealth Department of Human Services and Health conducted a study with families with very young children aged from birth to 6 years. This study demonstrated that without exception the primary desire of families was to care for their children at home. Despite this family goal, one-quarter of the families had already sought or were considering placement for children in this young age range. For these families there was a lack of congruence in everyday family life between meeting the needs of the disabled child and those of other family members; there was a lack of integration of the disabled child into everyday family life and the wider community; and, parents held concerns about the effect of the disabled child on their siblings now and in the future (Llewellyn et al., 1999).

In the current climate of community care, families are expected to care for their children with disabilities at home and most do so. As the Llewellyn et al. (1999) study demonstrated, some families continue to seek out-of-home placement for their disabled child, often in the face of considerable pressure not to do so. Why this is so is not well understood. The research on out-of-home placement has mainly focused on the negative impact of caring for children with disabilities, including studies of stress, depression, and grief. In contrast, personal accounts from families frequently identify positive outcomes from caring for their disabled child including, for example, a strengthening of family relationships, a focusing of career orientation, and an increased awareness and appreciation of difference and diversity. The findings from the Llewellyn et al. (1999) study suggest that further attention needs to be paid to what constitutes family well-being, the factors that enhance or diminish this and the relationship between family well-being and out-of-home placement. Focusing on the multi-faceted nature of family response to disability is congruent with family researchers paying increasing attention to family perspectives and the diversity of family experiences (Blacher & Hatton, 2002).

Examining the factors influencing out-of-home placement in families with older children of primary school age was one of the recommendations (Recommendation 1.2) of the Llewellyn et al. (1999) study. To carry out this work, Anne Clark (then Acting Chief Executive Officer, Spastic Centre of NSW) and Gwynnyth Llewellyn, School of Occupation and Leisure Sciences, University of Sydney sought funding from the ARC SPIRT Scheme in 1998. Experience from the Spastic Centre suggested that families with primary school age children were even more likely to be considering out-of-home

placement for their son or daughter with a disability. The Spastic Centre was also concerned to identify - ahead of time - those families more likely to place their children out of home so that they could tailor their services to more effectively meet their support needs.

Against this background of collaborative interest and concern, the Family Support and Services Project directed by Gwynnyth Llewellyn undertook this industry-university joint research project with Industry Partner, the Spastic Centre of NSW.

The broad purpose of the research project was to investigate family well-being and out-of-home placement tendency among families with children with disabilities and high support needs aged 6-13 years.

In doing so, we aimed to better understand differences in family well-being and the factors influencing this. The aims of the project therefore were to:

◆ Investigate family well-being as seen through the eyes of the primary parent-carer and within the context of everyday family life

◆ Investigate the relationship between family well-being and family decision-making about out-of-home placement

Eighty-one families from the Northern Metropolitan and Eastern Sydney regions took part in the study. The interviews with these families took place through 1999-2000. The Ecocultural Questionnaire and Ecocultural Family Interview format guided the semi-structured interviews (Ecocultural Scale Project, 1997). This format permits a narrative open-ended interviewing approach across ten domains of family life. The interview format is conversational in style and provides the opportunity for the primary parent-carer (most frequently the mother) to "tell their story". Interview participants also completed several standard measures on health, coping, child health and hassle and out-of-home placement tendency. The research design and measures are described in full in the following section.

Report format

Section 2 provides the conceptual framework, research design and the methods used in this study. The following four sections focus on reporting the findings. At the end of each section we summarize the findings under *Findings at a Glance*. Section 3 presents contextual data about the families who took part, including family composition, housing and income, education, employment and health status of primary parent-carers, and

schooling, friends, services, respite care and child health and hassle. In Section 4 we present the findings about primary parent-carer health status and their coping styles and the relationship between health status and coping style. Section 5 presents the conceptualization and measurement of family well-being used in this study and demographic profiles of the three family well-being groups identified. The relationship between coping styles and health status and family well-being are also explored. The differential impact of aspects of family everyday life on family well-being is also presented and the section concludes with a discussion of the factors influencing change in family well-being. Section 6 moves on to examine the findings on out-of-home placement tendency. The relationship between family well-being and out-of-home placement and the factors explaining variation in out-of-home tendency are also explored. This section concludes with a description of those families moving closer to out-of-home placement during the study period. The Conclusion, Section 7, summarizes the key findings from the study and suggests areas for further research directions.

Method

Contents

In 1998, there were 277,400 children in Australia aged 5-17 years (8% of all children in this age group) with a disability that involved specific restrictions (Australian Bureau of Statistics, 2000). With the ideological shift towards normalization of experiences for people with disabilities (Wolfensberger, 1983), the subsequent movement towards deinstitutionalisation, and the perceived expense of supporting people with disabilities from the public purse, the families of these children are under ever-increasing pressure to provide lifelong care for their children with disabilities at home (Cummins, 1997).

There is a large body of research focusing on the negative impact of caring for children with disabilities, including studies of stress, depression, and grief. *The perceived burden of caring* for disabled children has received a great deal of attention. Researchers have sought to measure both objective burden (e.g., number of visits to health professionals, use of respite) and subjective burden (e.g., personal perceptions including rating one's own health). Families of children with disabilities have been found to report greater levels of objective and subjective burden than their non-disability related counterparts (Carpiniello et al.,1995). Feelings of burden have been linked to, for example, levels of family support, problems with services, secondary problems of the child including maladaptive behaviours (Heller et al., 1994; Tetreault, Weiss-Lambrou, & Vezina, 1994), time spent in caregiving (Tetreault et al., 1994), and the use of certain coping strategies. Depression in families caring for children with disabilities has also been reported (e.g., Gowen et al., 1989), with 'helpfulness' of social support linked to decreased depression (Freedman, Krauss, & Seltzer, 1997).

The support available to families caring for children with disabilities has also received considerable attention. Research has focused on formal and/or informal sources of practical and emotional support, the effect of the child on spousal relationships and the level of support and family relationships. In addition to the informal support that comes from extended family, friends and neighbours, a variety of formal services have emerged to support families. Generally termed 'family support' these services include respite care, home and vehicle modifications, parent education, case management, counselling, nursing, therapies, home health care and financial assistance. Families of children with disabilities, particularly those with more severe disabilities, typically negotiate an array of services that are often diverse and fragmented (Marcenko & Smith, 1992). Services have been found to mediate against depression and to both contribute to and militate against stress and facilitate family well-being (Botuck & Winsberg, 1991; King et al., 1999; Sloper, 1999).

In sum, empirical work and position papers written from a professional perspective have served primarily to highlight *the difficulties and negative experiences* associated with caring for children with disabilities (Baine, 1993; Bruce, 1994; Helf & Glidden, 1998;

Koegel, 1992; Kazak, 1987; Quine, 1986). In general, investigators have focused on particular events or circumstances occasioning stress and the ongoing nature of the stresses and strains experienced by families (Beresford, 1996).

On the other hand, accounts of family life written by families identify positive experiences associated with caring for their disabled children including, for example, a strengthening of family relationships, a focusing of career orientation, and an increased awareness and appreciation of difference and diversity (Bowman & Virtue, 1993; Crutcher, 1990; Cunningham, 1989; Helsel, 1978; Scorgie & Sobsey, 2000). Accordingly over the last decade, family researchers have made greater efforts to investigate family experiences from the families' own perspective. Some researchers have focused on the rewards and satisfactions associated with caregiving (Grant & Nolan, 1993; Grant, Ramcharan, McGrath, Nolan, & Keady, 1998; Stainton & Besser, 1998). Others have addressed the strengths, resilience and hardiness of families of children with disabilities (Failla & Jones, 1991; Friend, 1991; Sloper & Turner, 1993).

Despite the overall 'tragic' tenor of the literature emphasizing the burden of disability the vast majority of children with disabilities live at home with their families. In industrialized countries funding support is typically provided to assist families to continue caring for their disabled children at home. Despite this, a significant number of families of children with disabilities and high support needs *continue to seek out-of-home placement*. A body of research has emerged on the relationship between the ongoing stress associated with family caregiving and the decision to seek out-of-home placement. Three multi-dimensional variables related to family stress - child, family and support characteristics – have been identified which appear to contribute to out-of-home placement.

Child characteristics related to out-of-home placement include behaviour, age and size (Blacher & Baker, 1992; Bromley & Blacher, 1991; King et al., 1999; Kobe, Rojahn, & Schroeder, 1991; Rousey, Blacher, & Hanneman, 1990; Tausig, 1985). Put simply, the older and larger the child (particularly if the child also has physical disabilities) and the more challenging the child's behaviour, the more likely families are to decide they can no longer cope. Family characteristics include caregiver stress and parental concern for the disabled child's siblings (King et al., 1999; Kobe et al., 1991; Llewellyn et al., 1999; Rousey et al., 1990; Stoneman & Berman, 1993). In other words, families who experience more stress and have heightened concerns about the health and well-being of their non-disabled children are more likely to seek placement. The final characteristic identified is the degree to which the family feels adequately supported. For those families who lack support from family members or friends and have little help with child-minding

or respite care, the risk of seeking out-of-home placement of their child is considerably increased (Bromley & Blacher, 1991; King et al., 1999; Kobe et al., 1991).

There has also been increasing interest in *understanding family well-being* a term often used synonymously with 'family quality of life' in families with children with disabilities. In a review of the literature pertaining to family quality of life/family well being, Cummins (1997) concluded that family quality of life comprises both culturally relevant objective and subjective measures of satisfaction across various life dimensions. Domains of family quality of life may include material well-being, health, productivity, intimacy, safety, community, and emotional well-being.

Family well-being in families of children with disabilities has been linked to the use of respite (Botuck & Winsberg, 1991), family-centred caregiving (King et al., 1999), child behaviour problems and socio-ecological factors such as family functioning and social support (King et al., 1999). Investigating family well-being in families of children with disabilities has the potential to focus on the diversity of family experiences and provide a useful insight into the caregiving experience. Understanding differences in family well-being may also assist in explaining why some families take action and seek out-of-home placement for their child with a disability while others do not.

Against this background the overall objective of the research team was to explore the usefulness of the concept of family well-being in alerting service providers to families 'at-risk' and particularly those at risk of placing their child with a disability out of home. While current programs target those families already known to be at-risk there is a dearth of information or practice tools to assist service providers in identifying – ahead of time – those families at risk of declining family well-being and/ or out-of home placement.

Specifically, the aims of the current study were:

   i. to investigate family well-being as seen through the eyes of the primary parent-carer and within the context of everyday family life, and

  ii. to investigate the relationship between family well-being and family decision-making about out-of-home placement.

Conceptual framework for the study

To explore everyday family life, the study adopted ecocultural theory and its accompanying instruments as the underpinning framework (Gallimore et al., 1989). Ecocultural theory, as the name suggests, comes from a blending of ecological and

cultural approaches to understanding family life. Ecocultural theory proposes that the central adaptive problem facing families - all families, whether or not they have a child with developmental disability - is the construction of a sustainable, meaningful and congruent daily routine of family life (Gallimore et al.,1993; Gallimore et al., 1989). This theory proposes that family members work individually and together to create a unique family setting - their ecocultural niche. The family creation of their ecocultural niche does not occur in a social vacuum; rather the setting mitigates and shapes the effects of the surrounding ecological and cultural forces.

The central task of organizing and sustaining the daily routine is said to occur through a process named family accommodation (Gallimore et al., 1989). Accommodation is not just a response to stressful situations, rather it is the central task of everyday family life. Ecocultural theory predicts that although there are common ecocultural features across families, families also have different goals, values and beliefs. Families also regard environmental factors differently, either as resources or constraints. Therefore a resource regarded positively by one family (e.g., extended family support) may be regarded as a constraint by another. This explains why families in ostensibly similar circumstances construct remarkably diverse family settings and make different family decisions (Gallimore et al., 1989).

Based on this ecocultural theoretical approach a series of instruments designed to gain understanding of everyday family life - from the families' perspective - have been developed and extensively used with families of children with developmental delay over the past decade (Ecocultural Scale Project, 2000, 1997a, 1997b, 1997c). Evidence of construct and concurrent validity of ecocultural assessment using these instruments has been reported (Nihira, Weisner, & Bernheimer, 1994; Schneider & Gearhart, 1998).

Research design

The three-year study reported here employed multiple methods to prospectively investigate family well-being over a two-year period. The core method was qualitative exploration of families' daily routines in ecocultural interviews with primary parent-carers. In addition, a range of standardized and non-standardized measures was used to gather demographic data and information on variables hypothesized to influence family well-being including primary parent-carer health, coping strategies, family functioning, and the impact of child health and hassle demands on everyday family life. These measures provided descriptive data, comparison with population norms, and an opportunity to investigate the relationship of particular variables to family well-being and tendency to out-of-home placement.

Planning and development

The core component of the study was the Ecocultural Family Interview & Questionnaire (Ecocultural Scale, 1997a, 1997b). These instruments were also used in the previous study with families of younger children with disabilities and high support needs (Llewellyn et al., 1999). During the development phase the most recent versions of the Ecocultural Family Interview, Questionnaire and Codebook were modified for middle childhood and the Australian context.

Selection of standardized measures to supplement the ecocultural instruments were made by the University-Industry Partner Project team in conjunction with a Parent Reference Group of eight mothers of children with disabilities. Four mothers had been involved in the previous study with younger children (Llewellyn et al., 1999). The remaining four responded to an invitation from the Industry Partner. Recommendations from piloting several measures of family coping, family functioning, family health and child health and hassle with the Reference Group resulted in selection of the following instruments and interview protocols and processes:

Family functioning: The McMaster Family Assessment Device (Epstein, Baldwin, & Bishop, 1983)

Caregiver coping: General & Specific Short Form of the Adult Coping Scale (Frydenberg & Lewis, 1997)

Caregiver health: SF-36 Item Health Survey (Ware et al., 1993)

Child Health and Hassle: Child Health & Hassle Scale (Gallimore et al., 1993)

Out of home placement tendency: Placement Tendency Index (Blacher, 1990).

Recruitment

The project team assembled a database of government and non-government services working with families with children with disabilities in the Northern Metropolitan and Eastern Sydney regions.

A workshop was held at the Spastic Centre of NSW in Allambie in May 1998 with representatives of all the agencies identified in Northern Metropolitan region. A similar workshop was arranged in the Eastern Sydney region in December 1998. The aim of the first workshop was to introduce the project to the agencies, to elicit their support in recruiting families, and to clarify the definition of disability and high support needs agreed for the project. Participants were given a project package containing family

referral forms and instructions. Workshop participants reached consensus on operational definitions of primary disability, primary disability categories, and potential inclusions in each category for the purposes of this study. This ensured as consistent as possible selection of families for recruitment across agencies. The primary criteria were (i) family with a child/ or children with a disability and high support needs aged between 6 and 13 years; and (ii) primary diagnosis of either intellectual disability, physical disability, vision impairment, hearing impairment, autism or ADD/ADHD.

Recruitment process

Representatives from 32 childhood and family service agencies in the Northern Metropolitan and Eastern Sydney regions identified and coded families on their databases that met the study criteria. Following removal of duplicate referrals, a total of 292 families meeting the study criteria were referred to the research team. Packages of coded invitations were prepared for each agency to forward to each family. Codes reflected the referring agency and family number thus allowing the researchers to trace the primary disability and age group of the child as required. A reminder letter was sent via service agencies to all families that had not responded within two months of the initial invitation. Families interested in participating returned their consent and contact information forms indicating the most appropriate time and place to contact them. Each family was then contacted to further discuss the nature of their involvement in the study and to confirm participation and contact details.

Method

Data collection: Ecocultural questionnaire and interview

Following initial telephone contact, each family was sent a modified form of the Ecocultural Family Interview Questionnaire (Ecocultural Scale, 1997b). This questionnaire aims to gather basic demographic data about mothers (the person in the primary mother role) and fathers (the person in the primary father role) on origin, language, education, study commitments, work situation and career beliefs. The remainder of the questionnaire comprises questions about the family, daily routine, social support, financial resources and child and family services and is completed by the person in the primary parent-carer role.

On return of the completed questionnaire, Samantha Whybrow, the research assistant for this project, contacted each primary parent-carer and arranged an interview at a convenient time to take place in the family home. The first wave of interviews took place between July 1998 and May 1999. These interviews were guided by having first read the

responses on the completed questionnaire and by using the modified version of the Ecocultural Scale Family Interview (Ecocultural Scale, 1997c, 2000) adapted for this project as previously described.

The Ecocultural Family Interview format comprises a narrative, open-ended interviewing approach across ten domains of everyday family life. These domains are: family subsistence base, service use, home/ neighbourhood, domestic workload, child care tasks and assistance with these, child peer groups, marital roles, instrumental and emotional support, father/ spouse role and parent information in relation to child disability. The interview format is conversational in style and provides the opportunity for the primary parent-carer (most frequently, the mother) to "tell their story". Interviews usually begin with an open-ended question such as "how are things going these days?"

By way of the Ecocultural Family Interview, the interviewer seeks to understand how a family constructs and sustains a daily routine that is meaningful, and that fits with the abilities and needs of members of the family and community. The interviewer thus seeks to answer four primary questions. Using these questions the interviewer seeks to explore family accommodation activity in everyday family life. The questions are:

- What is the primary parent-carer's point of view about their family adaptations? What do they see as their concerns, resources, constraints, goals, values and beliefs?

- What domains of everyday life are the families actively trying to change due to having a disabled child? What aspects of daily life are they not changing? Why not?

- What does the primary parent-carer feel are the key changes they would like in their everyday routine? What parts of their daily life do they feel are "not working"?

- What parts of their daily life do they feel should not be changed? What do they expect for their child's future? For the family's future?

Interviews with primary parent-carers were tape-recorded and later coded using a modified Ecocultural Family Interview Codebook (Ecocultural Scale, 1997a). A copy of the adapted Ecocultural Family Interview format and modified Ecocultural Family Interview Codebook is available from the first author on request.

Between October 1999 and February 2000 all participating families were contacted to take part in a second interview. At the time of this call, the interviewer arranged a mutually convenient time and location for the second interview and confirmed contact details. A photocopy of the completed Ecocultural Family Interview Questionnaire (Ecocultural Scale, 1997c) from their first interview was posted to primary parent-carers for review and return with any changes prior to the second interview. The Ecocultural Family Interview format and Questionnaire also guided the second interview in a similar fashion to the first.

Data collection: Primary parent-carer health, coping, family functioning, child health and hassle and out-of-home placement considerations

The additional measures in questionnaire or scale form on caregiver health, coping strategies, family functioning, child health and hassle and out-of-home placement were either completed during the interview or left with the primary parent-carer for later completion and return. Completing these measures also facilitated discussion and generated additional narrative data about placement tendency and child health issues.

The Placement Tendency Index (Blacher, 1990) is a five-point scale where the primary parent-carer was asked to indicate their thoughts in relation to out-of-home placement according to a scale that ranges from "never having considered placement" to having "made all arrangements for placement." The primary parent-carer was then asked to describe why they perceived themselves to be at the indicated point.

The Child Health and Child Hassle Scale (Gallimore et al., 1995). On this scale primary parent-carers were asked to identify any medical, behavioural, communication, interaction, responsiveness and appropriacy problems associated with their child with high support needs. They were then asked to rate each area on an eight-point scale item in terms of the "hassle", with hassle defined as the extent of the child's impact on the daily routine of family life.

The final measure completed at interview was the McMaster Family Assessment Device (Epstein et al., 1983). This is a 60 item self-report questionnaire designed to measure family functioning. The findings from this questionnaire are not presented as the binary division recommended by the authors was not sufficiently sensitive to differentiate families in this study on 'family functioning'.

The following questionnaires were left for completion and return to the research team within two weeks of the interview. The General and Specific Short Form of the Adult Coping Scale (Frydenberg & Lewis, 1997) which requires answers on overall coping strategies (General Form) and strategies in relation to a specific, self reported stressful situation (Specific Form). The SF-36 Item Health Survey (Ware et al., 1993) which requires answers on 36 questions using a Likert scale and dealing with a range of physical, social and health related dimensions.

Participation and continuation rate

Eighty-six of the 292 eligible families accepted the invitation to participate, 42 declined to participate and a further 164 families did not respond. At the time of initial contact, an additional 5 families withdrew from the study – two families withdrew due to time constraints, 2 families withdrew due to health problems of the primary parent-carer or a family member, and one family withdrew following the death of the child with high support needs. This resulted in an overall sample of 81 families (27.7%) and an acceptance rate of 29.4%. Given the many time demands on these families and the amount of posted material received from service agencies this acceptance rate while lower than desired was considered satisfactory.

Several measures were employed to maintain the original sample of 81 families during the life of the study. At the initial interview, families were encouraged to call the research team should they have any concerns or queries. Families were also asked to indicate a 'secondary contact person' that would be able to locate the family should the research team not be able to contact them via the supplied contact details. All families and service agencies also received project updates between interviews. These measures resulted in a high retention rate of 91.3%. Only three families did not participate in a second interview. One family could not be contacted, one family withdrew citing personal reasons, and a third family withdrew citing other family demands.

Data analysis

One coder developed transcript summaries and coded a total of 159 taped interviews 'blind' to responses on the standardized and non-standardized measures. A set of coding decision notes was developed by discussion at team meetings to supplement the coding descriptions presented in the Ecocultural Family Interview Codebook. Of the 51 ecocultural items, three were deleted prior to coding based on the high percentage of 9 (not applicable) codes. These were items 9,10 and 47, which deal with insurance cover for child and family and diversity in family ethnic and cultural models. Coding for each item was conducted as follows:

- ◆ 0, 1 or 2 (low) - there is little or no activity related to the child with high support needs or effect on the family

- ◆ 3, 4 or 5 (moderate) - there is some evidence of activity or effect related to the child with high support needs, but it is not a dominant theme for this family

- ◆ 6, 7 or 8 (high) - activity or effect related to the child with high support needs is a dominant theme for this family

- ◆ 9 - Not applicable.

Review of this coding by the first author on a random sample of approximately one quarter of first and second interviews resulted in 90% agreement.

Following scoring on individual items each family was scored on three summary dimensions on a scale of one through eight drawing on all the insights gathered throughout the interview and coding process. Scoring criteria are provided in the Ecocultural Family Interview Codebook. Definitions of each summary scale with some examples of scoring criteria are:

Meaningfulness of daily routine and appropriateness to family's goals and values
- 0, 1 or 2 = Low. There is little evidence of meaningfulness (e.g. child attends after-school care with typically developing children only because it is convenient for working parents, not because the parents value the interaction with typically developing peers.)
- 3,4 or 5 = Medium. Some evidence of meaningfulness (e.g. child participates in youth group at church because parents believe religious training is important.)
- 6,7 or 8 = High. Much evidence of meaningfulness (e.g. parents include child with severe behaviour problems in all family activities because they value togetherness.)

Congruence between competencies and needs of child and of other family members
- 0, 1 or 2 = Low. Little evidence of congruence (e.g. parents make no effort to protect sibling's belongings from destructive behaviour of child with delays.)
- 3,4 or 5 = Medium. Some evidence of congruence (e.g. high achieving parents avoid placing unrealistic academic expectations on child with learning problems.)
- 6,7 or 8 = High. Much evidence of congruence (e.g. parents plan occasional family outings without child, so that older siblings can experience age appropriate activities.)

Sustainability of daily routine in face of obstacles; ability of parents to keep routine by using variety of resources
- 0, 1 or 2 = Low. Little evidence of sustainability (e.g. single mum tries to carry through on daily exercises prescribed by the physiotherapist although she has a full-time job, two other small children and no available help.)
- 3, 4 or 5 = Medium. Some evidence of sustainability (e.g. family uses grandparents as babysitters so they can go out together one night per week.)
- 6, 7 or 8 = High. Much evidence of sustainability (e.g. home therapy program is carried out with help of older siblings, neighbours and live-in domestic help. When neighbours move away, parents are able to recruit replacements.)

The composite of these three summary scales – meaningfulness, congruence and sustainability – comprise the *measure of family well-being* used in this study. This composite score is indicative of the extent to which a family has a meaningful and sustainable everyday family routine that is congruent with their beliefs, values and goals for their family.

SUMMARY

◆ The literature on families with children with disabilities focuses more on stress and burden than on the positive aspects of families' lives. In contrast, this study focused particularly on family well-being in the context of everyday family life. The focus of the study was on factors influencing family well-being and the relationship between family well-being and families seeking out-of-home placement for their child with a disability and high support needs.

◆ Eighty-one families from the Northern Metropolitan and Eastern Sydney regions took part in two narrative interviews around 12-18 months apart. These interviews addressed everyday life as seen through the eyes of the primary parent-carer. Participants also completed questionnaires about their health, family functioning, coping strategies, child health and hassle and out-of-home placement considerations.

The Families

Contents

Eighty-one families with children with disabilities and high support needs from the Northern metropolitan and Eastern Sydney region took part in this study. This section presents demographic data on these families, the primary parent-carers and the children.

Family composition, housing and income

Of the eighty-one families, 67 (83%) were two parent families and 12 (15%) were single parent families (all mothers). There was one extended family (three generations sharing the same household) and one family where the child with a disability and high support needs lived with his grandparents (grandmother nominated herself as the primary parent-carer).

There were, on average, between four and five people (range = 2-12) living in each household. The number of children ranged from one to ten, averaging two to three, including the child with a disability. In sixteen percent (n=13) of families, the child (6-13 years) with a disability and high support needs had at least one sibling with special needs. Of these 13 families, one included a sibling with a diagnosed eating disorder; five families had more than one child with autism, and there were seven families where a sibling had some other form of disability.

Socio-economic circumstances

At least one parent worked in 93% of participating families; 49% were two-income families and 7.5% had no employment related income. Sixty-seven percent of mothers and 92% of fathers were in some form of paid employment, equal or better to the overall labour participation rate of 66.2% for the geographical region (Australian Bureau of Statistics, 1996) and that of carers of working age (men 76%, women 57%) in NSW (Australian Bureau of Statistics, 2001).

Most of the families were either purchasing (50.6%) or owned (25.9%) their home; nineteen families (23.5%) were renting or living in shared-accommodation (e.g. with extended family). Approximately half (51%) had a net income of greater than $60,000 per annum. About one-third (32.9%) of the families had a net income of between $30,001 and $60,000, and roughly one in six families (16%) were living on less than $30,001 per annum.

Twenty primary parent-carers (approximately one in four) reported that their families were in good financial condition. Another 37 (46%) indicated that their family income was adequate, although little saving was possible. Of concern is the finding that 24 (30%) families reported their net income to be either insufficient or barely sufficient to meet their basic needs.

Education, employment & health status of primary parent-carers

Of the 81 primary parent-carers interviewed, 77 were mothers (including one grandmother) and 4 were fathers. Mothers' ages ranged from 28 to 74 years, with a mean of 42 years. Fathers' ages ranged between 36 and 64 years, with a mean of 46 years. All primary parent-carers were English-speaking. Approximately 70% of both mothers and fathers were Australian born non-Aboriginal. A further 20% originated from English-speaking countries outside of Australia, such as the United Kingdom, New Zealand and North America.

Education & employment

More than half (52%) the mothers had tertiary (36%) or post-graduate (16%) qualifications. One father had tertiary qualifications. Another 23% of the mothers and one father reported having college or TAFE training. By comparison, ABS data (1996) indicate that 22% of the population for Northern Metropolitan and Eastern Sydney and just 11% of the general population have tertiary or post-graduate qualifications. These figures suggest that the primary parent-carers comprise a highly educated group.

At I1, fourteen (18%) of the 77 mothers and two of the four fathers were employed full-time. A further 30 (39%) mothers were working part-time. The other 33 (43%) mothers and two fathers identified themselves as full-time homemakers; eight (10%) of these mothers engaged in occasional or casual employment.

Social support

In two-parent households, 57 out of 68 (84%) reported their spouse was a strong source of support. By contrast, 9 out of 13 (69%) single mothers reported that their ex-partner was no support at all.

Approximately half of the primary parent-carers (51%) reported that professionals provided strong support. For just over one-third (35%), the primary parent-carer's own parents were also a significant source of support.

Friends and/or neighbours provided strong support for about one in four primary parent-carers. Support from parent-in-laws and other relatives was less substantial with just 17% and 16% of primary parent-carers respectively identifying this source of support.

The children with disabilities and high support needs

Of the 81 children with disabilities and high support needs there were 50 boys (62%) and 31 girls (38%). At the time of recruitment, the children's ages ranged between 6 and 13 years, with a mean age of 9.4 years (std = 2.2 years). Classified by primary diagnosis, there were 35 (43%) children with a physical disability, 33 (41%) children with intellectual disability, and 13 (16%) children with autism.

Schooling

Forty children, or roughly one in two (49%), attended a special school. This is more than six times the overall percentage of children with disabilities (aged 6 to 17) attending special schools in NSW (Australian Bureau of Statistics, 2000). Another 27 children, comprising one-third of the sample, were in a special class at a regular school. Fourteen children (17.3%) were fully integrated with or without the assistance of a special teacher's aide.

Children with intellectual disability or autism were significantly less likely to be fully integrated into mainstream classes ($\chi2$=17.0, p<. 005). More than one-third (34.3%) of children with a physical disability were fully integrated; only 6.1% of children with intellectual disability and none of the children with autism were integrated into mainstream classes.

Friends, services and respite care

Based on primary parent-carers' reports, approximately half the children (40) did not have friends without special needs. Thirty children had between one and three non-disabled friends and 11 children had more than four. Friends with special needs were more common, with 20 children having more than four, and 30 children having between one and three.

On average, the children received two specialist services (such as occupational therapy, physiotherapy and speech pathology) at their school and one service outside of school. The children attending special schools received significantly more specialist services in school (F=6.4, p<. 005), while children who were fully integrated accessed a greater number of specialist services outside school, although between-group differences were not statistically significant.

Forty-eight children (59%) attended some form of respite care at least once per month; 23 children (28%) did so at least fortnightly. A small number of children (13, 16%) attended formal after-school programs.

Child health and hassle

Using the Child Health and Hassle Scale (Gallimore et al., 1995) primary parent-carers were asked to identify the medical, behavioural, communication, interaction, responsiveness and appropriacy problems that were associated with their child with high support needs. Following medical/health care needs, five dimensions of behaviour are distinguished to form six subscales as follows:

i.   Medical/health care needs, e.g. unusual care demands

ii. Aberrant behaviours, e.g. self harm, destructive, tantrums, uncooperative

iii. Communication, e.g. does not speak or difficult to understand

iv. Interaction, e.g. extremely active, plays alone, needs constant monitoring

v.   Responsiveness, e.g. ignores, does not respond to others

vi. Appropriacy, e.g. age inappropriate conduct

Primary parent-carers then rate on an eight-point scale the level of "hassle" or demand placed on the family by the child on each of the six subscales. A score of 8 indicates very high levels of demand (and associated family activity) whereas a score of 0 indicates no problem or no demand. A Global Child Hassle score is computed by summing subscale scores.

On subscale *child's medical/health care need*s, the scores ranged from 0 to 8 with a mean of 3.1 (std = 2.7) at Interview 1 (I1), and 3.8 (std =2.8) at Interview 2 (I2). Hereafter, Interview 1 and Interview 2 are referred to as I1 and I2 respectively. Using I1 data only and Analysis of Variance (ANOVA) within group differences were examined to determine whether level of child medical/health care demand was associated with primary diagnosis, school placement and/or use of respite care. No significant differences ($p < .05$) were found.

On the other five subscales scores also ranged from 0-8. At I1, mean scores ranged from a low of 2.94 on child responsiveness to a high of 4.22 on child interaction. I2 findings were consistent with this with mean scores ranging from a low of 2.91 on child responsiveness to a high of 4.17 on child interaction. Using I1 data only and ANOVA, disability groups (physical, intellectual, autism) differed significantly on Aberrant Behaviours ($F=11.1$, $p < .001$), Interaction ($F=6.7$, $p < .005$), Responsiveness ($F=15.1$, $p < .001$), Appropriacy ($F=26.4$, $p < .001$) and Global Child Hassle ($F=13.1$, $p < .001$). Bonferroni contrasts revealed that ratings for children with intellectual disability and those with autism were not significantly different on any subscale. The significant difference was between ratings for children with a physical disability and both other disability groups. Specifically, the behaviours of children with a physical disability were typically perceived to be less 'hassle' or less demanding on the family than the behaviours of children with intellectual disability and children with autism.

School placement groups (special school, special class/regular school and fully integrated) differed significantly on Aberrant Behaviours (F=4.8, p<. 05), Communication (F=7.9, p<. 005), Interaction (F=12.8, p<. 001), Responsiveness (F=15.0, p<. 001), Appropriacy (F=12.0, p<. 001) and Global Child Hassle (F=17.3, p<. 001). Bonferroni contrasts showed that all three groups differed significantly (p<. 05) from one another on Global Child Hassle and the Responsiveness subscale, with children attending special schools deemed to be the most demanding and those who were fully integrated the least demanding. Children in the fully integrated group were also significantly (p<. 05) less demanding than children in both other groups (no difference) on Aberrant behaviours, Interaction and Appropriacy subscales. Children attending special schools were deemed to be significantly (p<. 05) more demanding than children in both other groups (no difference) on the Communication subscale.

Use of respite care groups (never, at most monthly, at least fortnightly) differed significantly on Communication (F=7.3, p<. 005), Interaction (F=4.9, p<. 05), Appropriacy (F=6.4, p<. 005) and Global Child Hassle (F=6.7, p<. 005). Bonferroni contrasts revealed that those children who attended respite care at least fortnightly were deemed to be significantly (p<. 05) more 'hassle' (or more demanding) than both other groups (who did not differ) on Global Child Hassle as well as Communication and Appropriacy subscales. On the Interaction subscale, children who attended respite care at least fortnightly were significantly (p<. 05) more demanding than children who never attended respite care.

Primary parent-carer satisfaction with services

Primary parent-carers were generally satisfied with education professionals: 74.3% were 'somewhat satisfied' or 'satisfied' with special education professionals, 75.3% with regular education professionals, and 85.2% with their child's current teacher. They were less pleased with the education system as a whole, with 41.9% feeling dissatisfied or somewhat dissatisfied with the school system.

Primary parent-carers were less satisfied with medical and therapy related personnel and the associated health system than with teachers. Approximately 38% were 'dissatisfied' or 'somewhat dissatisfied' with the community care system, 32% with the health care system, 30% with medical advice, and 27% with allied health advice. Examination of qualitative data revealed that dissatisfaction with community care services comes mainly from the limited and inflexible nature of home care services.

FINDINGS AT A GLANCE

This section has reported findings about the families who took part in the study and their circumstances.

- Most were two parent families with higher educational qualifications than the general population and a better employment rate than other carers in NSW.

- Although few families had low incomes, around 30% of the families reported insufficient income to meet their needs.

- One in two of the children attended special schools, a figure six times higher than the NSW percentage and one that suggests these children have high to very high support needs.

- Primary parent-carers were generally satisfied with education professionals although less so with the education, health and community care systems.

Health and Coping Styles

Contents

Aim

To investigate the health status and coping styles of primary parent-carers of children with disabilities and high support needs aged 6-13 years.

Objectives

- ◆ To compare the health of primary parent-carers of children with disabilities and high support needs with Australian population norms

- ◆ To explore the coping styles employed by primary parent-carers of children with disabilities and high support needs

- ◆ To examine the relationship between primary parent-carer health and coping style

Health status of primary parent-carers

Research question: *Do primary parent-carers of 6-13 year old children with disabilities and high support needs experience poorer health than their peers in the Australian population?*

The MOS 36 item Short Form Health Survey (SF36) was used to assess the health status of primary parent-carers. This widely used self report health survey, for which Australian norms have been published, contains 36 questions in eight subscales to provide measures of perceived physical and mental health and the impact of health status on daily life (see Table 1). Higher scores on each subscale (range zero to 100) indicate better health status.

A total of 78 primary parent-carers (74 women and 4 men) completed and returned the SF36 after I1, and 65 (62 women and 3 men) did so after I2. The time lapse between interviews varied from 11 to 15 months. Cronbach alpha coefficients were computed to assess the internal consistency or reliability of each SF36 subscale using I1 data. The alpha coefficients ranged from 0.72 (social functioning) to 0.90 (physical functioning), indicating an acceptable level of reliability for group comparisons. Replication of findings from I1 data at I2 suggests robust results.

Table 2 shows confidence intervals for the mean SF36 subscale and component scores for the Australian population and primary parent-carers at I1 and I2.   Primary parent-carers reported significantly poorer health on five out of eight SF36 subscales at I1 and six out of eight at I2. The disparity in health status between the sample and population mean SF36 subscale scores is shown in Figure 1. The standout finding—and one of great concern—is that this group of primary parent-carers consistently (I1 & I2) reported significantly poorer mental health (see Mental Component Scale scores) compared to Australian norms.

Table 1:   SF36 Subscales and descriptions

Subscale	Description
Physical Functioning (PF)	How limited people are by health in performing a range of typical physical activities, such as bathing and dressing
Role Physical (RP)	Effects of physical health on work or other daily activities
Bodily Pain (BP)	Extent of any pain and consequent limitations
General Health (GH)	Self assessed health status and perceptions of health relative to health of those around them
Vitality (VI)	Energy and fatigue levels
Social Functioning (SF)	Impact of physical and/or emotional problems on social activities
Role Emotional (RE)	Effects of emotional problems on work and other regular daily activities
Mental Health (MH)	Amount of time a person experiences feelings of nervousness, anxiety, depression and conversely, peace and happiness.
Physical Component Scale (PCS)	Physical health summary measure calculated on eight SF-36 scales
Mental Component Scale (MCS)	Mental health summary measure calculated on eight SF-36 scales

Table 2:   SF36 – 95% confidence intervals for the mean

	Australian norms[a]	Sample at I1 (n=77)	Sample at I2 (n=65)
Physical functioning	[82.1 – 82.9]	[79.3 – 88.0]	[79.3 – 93.0]
Role Limit Physical	[79.0 – 80.6]	[60.9 – 77.6]*	[58.3 – 78.4]*
Bodily pain	[76.2 – 77.4]	[68.1 – 78.2]	[58.1 – 71.9]*
General Health	[71.2 – 72.0]	[67.8 – 76.4]	[62.4 – 73.2]
Vitality	[64.1 – 64.9]	[44.8 – 53.7]*	[42.6 – 52.0]*
Social Functioning	[84.5 – 85.3]	[68.8 – 79.2]*	[69.1 – 81.3]*
Role Limit Emotional	[82.2 – 83.4]	[49.9 – 68.9]*	[62.5 – 80.2]*
Mental Health	[75.5 – 76.3]	[50.4 – 57.8]*	[59.3 – 67.8]*
Physical Component Scale	[49.5 – 49.9]	[51.2 – 54.9]*	[46.1 – 52.0]
Mental Component Scale	[49.9 – 50.3]	[36.5 –41.9] *	[40.0 – 46.1]*

[a]   age standardised score

*   indicates a statistically significant difference (p<.05) between sample and Australian norms

Figure 1: Health status of primary parent-carers: Comparison with Australian norms.
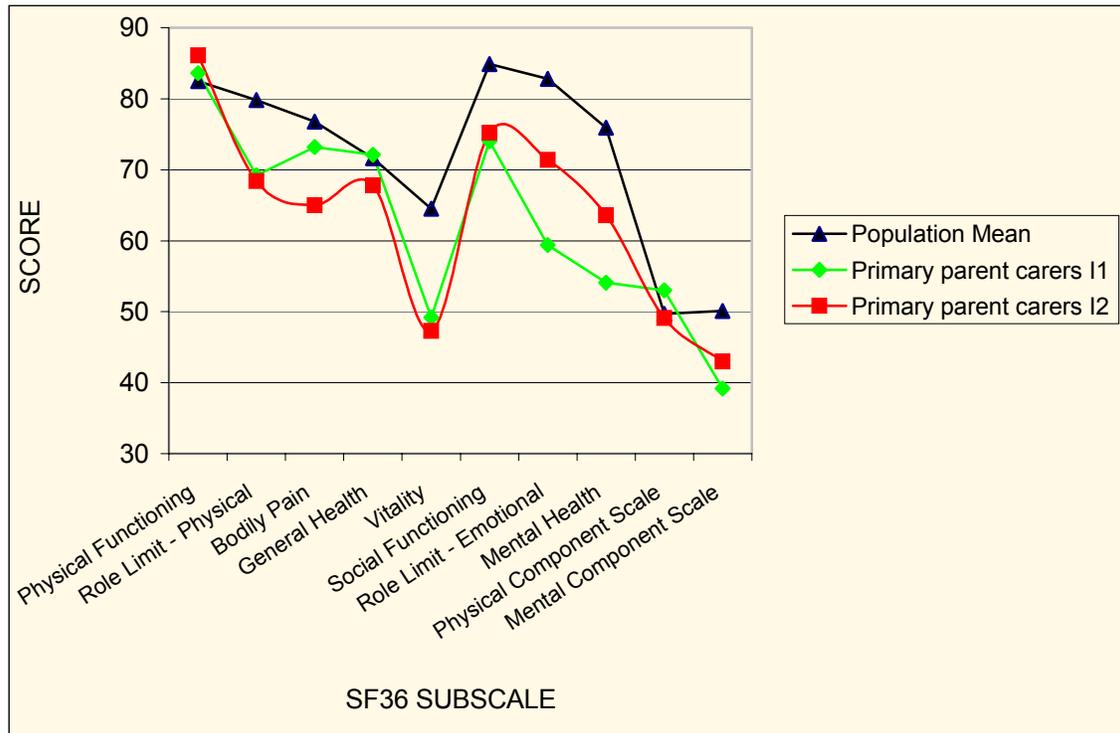
Coping styles of primary parent-carers

Research question: What coping styles/strategies do primary parent-carers of children with disabilities and high support needs employ?

The coping strategies/styles of primary parent-carers were assessed using the Adult Coping Scale (Frydenberg & Lewis, 1997). The General Short Form consists of 20 items assessing coping strategies. Respondents indicate how frequently each strategy is employed on a five point scale from 'Doesn't apply or don't do it' through to 'Used a great deal'. From these responses a profile of coping styles is generated. Four coping styles are distinguished including *Dealing with the Problem*, *Non-productive Coping*, *Optimism* and *Sharing*. The specific coping strategies associated with each coping style are listed in Table 3.

Table 4 shows the percentage of primary parent-carers employing each coping style 'Rarely' ('Doesn't apply or don't do it' or 'Used very little'), 'Sometimes' ('Used sometimes') and 'Often' ('Used frequently' or 'Used a great deal') at I1 and I2.

Table 3: Coping styles

Styles	Strategies
Dealing with the problem	Physical recreation, working hard, looking after oneself, focusing on problem solving, humour, improving relationships, seeking relaxing diversions
Non-productive coping	Getting sick, letting off steam, wishful thinking, self-blame, keeping to self, ignoring the problem, worrying
Optimism	Seeking spiritual support, focusing on the positive, wishful thinking, seeking relaxing diversions
Sharing	Seeking social support, social action, seeking professional help

Table 4: Profile of Coping Styles

	Interview 1			Interview 2		
	Rarely	*Sometimes*	*Often*	*Rarely*	*Sometimes*	*Often*
Dealing with the problem	17.8%	64.4%	17.8%	19.8%	53.1%	27.2%
Non-productive Coping	53.4%	41.1%	5.5%	45.7%	33.3%	21%
Optimism	37%	52.1%	11%	37%	38.3%	24.7%
Sharing	45.2%	24.7%	30.2%	27.2%	27.2%	45.7%

The most 'Often' used coping style at I1 and I2 was *Sharing*. This coping style incorporates strategies such as talking/sharing with others, going to meetings that look at the problem, and asking a professional person for help. *Non-productive Coping* was the most 'Rarely' used coping style. This style incorporates strategies such as worrying, daydreaming that things will turn out well, blaming yourself, consciously 'blocking out' the problem and getting sick. Nevertheless, approximately one in two primary parent-carers reported using *Non-productive Coping* strategies at least sometimes.

Health status & coping style

Research question: Is there a relationship between the health status of primary parent-carers and their coping style/s?

The relationship between coping styles and SF36 sub-scale and component scores was examined by computing Spearman's rho correlation coefficients. A statistically significant correlation ($p<.05$) was found between use of *Non-productive Coping* strategies and the Mental Component scores at I1 (r= -.37) and I2 (r= -.34). While this finding clearly demonstrates an association between *Non-productive Coping* and poor mental health, no causal relationship can be inferred. The relationship is probably bi-directional; that is, more frequent use of *Non-productive Coping* strategies results in poorer mental health and vice versa.

Table 5 lists the significant correlations (Spearman's rho coefficients) found between SF36 subscale and component scores and use of *Non-productive Coping* strategies. Notably, a significant correlation was found between *Non-productive Coping* and seven out of eight SF36 subscales at I1, and six out of eight at I2.   No significant correlation was found between any SF36 subscale and the coping styles of *Dealing with the Problem*, *Sharing* and *Optimism*, with one exception. At I1 a significant correlation was found between Mental Health and *Optimism* (r=.25)

Table 5:   Correlations between SF36 scores and *Non-Productive Coping* style

	Non-PC I1	Non-PC I2
Physical functioning	r = -.34 (p<.005)	r = -.26 (p<.05)
Role Limit Physical	r = -.35 (p<.005)	
Bodily pain	r = -.26 (p<.05)	r = -.25 (p<.05)
General Health		r = -.28 (p<.05)
Vitality	r = -.33 (p<.005)	r = -.33 (p<.01)
Social Functioning	r = -.28 (p<.05)	r = -.29 (p<.05)
Role Limit Emotional	r = -.31 (p<.01)	
Mental Health	r = -.39 (p<.001)	r = -.51 (p<.001)
Physical Component Scale	r = -.29 (p<.05)	
Mental Component Scale	r = -.37 (p<.005)	r = -.34 (p<.01)

FINDINGS AT A GLANCE

♦ Primary parent-carers of children with disabilities and high support needs suffer poorer health compared to Australian population norms. Poor mental health in particular is hindering their everyday functioning.

♦ Most primary parent-carers like to 'deal with any problems arising' and turn to significant others for support, that is, they use *Sharing* as a productive coping style. However, roughly one in two primary parent-carers reported using *Non-productive Coping* strategies at least sometimes.

♦ There is a strong association between the use of *Non-productive Coping* strategies and the mental health status of primary parent-carers.

Family Well-being

Contents

Aim

To investigate the well-being of families with children with disabilities and high support needs aged 6-13 years.

Objectives

- ◆ To assess the well-being of families with children with disabilities and high support needs

- ◆ To examine the relationship between primary parent-carer coping style, health status and family well-being

- ◆ To identify the strongest eco-cultural influences on family well-being

- ◆ To develop a profile of families and their well-being to describe those who may need extra assistance

Measuring family well-being

The measure of family well-being used in this study is the composite of the three summary scales – meaningfulness, congruence and sustainability - scored following review of the Ecocultural Family Interview and Questionnaire data. This composite score is indicative of the extent to which a family has established a meaningful, congruent and sustainable day-to-day routine.

Internal consistency of the three summary scales was examined prior to using the composite score. The internal consistency was found to be high, with Cronbach alpha coefficients of 0.83 and 0.88 at I1 and I2 respectively. The Kolmogorov-Smirnov statistic with Lilliefors significance level was used to test the hypothesis that family well-being scores were normally distributed. The hypothesis was accepted for I1 and I2 data, with the significance level set at $p < 01$.

Family well-being groups

Family well-being scores ranged from 4 to 24 with a mean of 14.3 (std = 4.52) at I1 and 13.52 (std = 5.12) at I2. On average, family well-being did not vary significantly between I1 and I2.   Three well-being groups were distinguished based on standard deviation as follows:

◆   'Struggling' families: family well-being scores one standard deviation or more below the mean

◆   'Doing OK' families: family well-being scores within one standard deviation either side of the mean

◆   'Thriving' families: family well-being scores one standard deviation or more above the mean.

Table 6 shows the distribution of families across these three groups at I1 and I2.   Three families withdrew from the study between I1 and I2, leaving a total of 78 families at I2.

Table 6:   Well-being groups

	Well-being Group	**Range**	**Count**	**%**
Interview 1: Mean = 14.3 sd = 4.45	Struggling	<10	17	21.0%
	Doing OK	10 – 19	44	54.3%
	Thriving	>19	20	24.7%
Interview 2:[a] Mean = 13.5 sd = 5.12	Struggling	< 8	23	29.5%
	Doing OK	8- 19	34	43.6%
	Thriving	>19	21	26.9%

Demographic profiles for family well-being groups

Research question: Are there differences in the demographic characteristics of the family well-being groups?

Child characteristics

Data on child sex, age, disability and school placement are presented in Table 7.   No statistical association was found between family well-being and child sex, age or disability.

A significant association was found between well-being group and school placement. Fully integrated children were significantly over-represented in the Thriving group at I1 ($\chi2$=21.4, p<. 001) and I2 ($\chi2$=12.1, p<. 05).

Given the previously reported association between school placement and global child hassle (in particular, problematic behaviours), Analysis of Covariance (ANCOVA) was employed to determine whether school placement continued to show a main effect on family well-being after controlling for 'global child hassle'. No main effect was found for school placement at I1 (F=1.1, p=. 34) or I2 (F=. 1, p=. 90).   However, a significant relationship between global child hassle and family well-being was found at I1 (F=13.5, p<.001) and I2 (F=21.5, p<.001). A likely interpretation of these findings is that school placement is a proxy indicator of the demands (or activity) generated by the child's behaviours.

Primary parent-carer characteristics

Data on primary parent-carer sex, age, marital and employment status are presented in Table 8.   No association was found between family well-being and age or employment status. A significant association was found between family well-being and marital status at I1 ($\chi2$=10.5, p<.01) and I2 ($\chi2$=7.8, p<.05). Specifically, single mothers were over-represented in the Struggling group.

Table 7:   Child characteristics and family well-being groups

	Struggling		Doing OK		Thriving	
	I1 (n=17)	I2 (n=23)	I1 (n=44)	I2 (n=34)	I1 (n=20)	I2 (n=21)
Sex (m/f)	11/6	14/9	29/15	21/13	10/10	12/9
Age (years)	10.24		9.11		9.25	
Disability						
Physical	6 (35.3%)	8 (34.8%)	17 (38.6%)	15 (44.1%)	12 (60%)	12 (57.1%)
Intellectual	7 (41.2%)	10 (43.5%)	19 (43.2%)	14 (41.2%)	7 (35%)	7 (33.3%)
Autism	4 (23.5%)	5 (21.7%)	8 (18.2%)	5 (14.7%)	1 (5%)	2 (9.5%)
Schooling						
Fully integrated[a]	2 (11.8%)	2 (8.7%)	2 (4.5%)	5 (14.7%)	10 (50%)	7 (33.3%)
Special class[b]	5 (29.4%)	4 (17.4%)	19 (43.2%)	16 (47.1%)	3 (15%)	8 (38.1%)
Special School	10 (58.8%)	17 (73.9%)	23 (52.3%)	13 (38.2%)	7 (35%)	8 (38.1%)

(a) Fully integrated, with/without special assistance

(b) Special class in a mainstream school

Table 8:   Primary parent-carer characteristics and family well-being groups

	Struggling		Doing OK		Thriving	
	I1 (n=17)	I2 (n=23)	I1 (n=44)	I2 (n=34)	I1 (n=20)	I2 (n=21)
Sex (f/m)	16/1	22/1	41/3	32/2	20/0	20/1
Age (years)	45.4		41.4		40.7	
Marital status						
Sole parent	7 (41.2%)	7 (30.4%)	5 (11.4%)	5 (14.7%)	1 (5%)	0 (0%)
Two parent	10 (58.8%)	16 (69.6%)	39 (88.6%)	29 (85.3%)	19 (95%)	21 (100%)
Employment status						
Unemployed	8 (47.1%)	9 (39.1%)	12 (27.3%)	12 (35.3%)	7 (35%)	6 (28.6%)
Part-time/casual	8 (47.1%)	9 (39.1%)	22 (50%)	19 (55.9%)	8 (40%)	7 (33.3%)
Full-time	1 (5.9%)	5 (21.7%)	10 (22.7%)	3 (8.8%)	5 (25%)	8 (38.1%)

Family characteristics

Data on household composition, housing and income are presented in Table 9. No relationship was found between family well-being and household composition or housing. A significant relationship was found between family well-being (scale 0-24) and income (eight-point scale) at I1 (Spearman's rho=.452, p<.001) and I2 (Spearman's rho =.508, p<.001). This positive correlation suggests that total family income and family well-being co-vary. Families with net incomes below $30,001 were more likely to be in the Struggling group. Another significant association was between family well-being and having more than one child with special needs at I1 ($\chi2$=8.5, p<.05). Families with more than one child with special needs were more likely to be in the Struggling or Doing OK groups.

Table 9:   Family characteristics and family well-being groups

	Struggling		Doing OK		Thriving	
	I1 (n=17)	I2 (n=23)	I1 (n=44)	I2 (n=34)	I1 (n=20)	I2 (n=21)
Housing						
Rent/share	5 (29.4%)	7 (30.4%)	11 (29.4%)	7 (20.6%)	3 (15%)	3 (14.3%)
Home/mortgage	11 (64.7%)	12 (52.2%)	22 (50%)	20 (58.8%)	8 (40%)	9 (42.9%)
Own home outright	1 (5.9%)	4 (17.4%)	11 (25%)	7 (20.6%)	9 (45%)	9 (42.9%)
Income *per annum*						
<$30,001	6 (40%)	6 (30%)	5 (12.5%)	5 (17.9%)	0 (0%)	0 (0%)
$30,001-$60,000	4 (26.7%)	9 (45%)	16 (40%)	9 (32.1%)	3 (20%)	2 (10.5%)
>$60,000	5 (33.3%)	5 (25%)	19 (47.5%)	14 (50%)	12 (80%)	17 (89.5%)
Household composition						
Mean no. Adults	1.88	1.96	2.07	2.15	2.10	2.00
Mean no. Children	2.35	2.48	2.55	2.59	2.85	2.81
> 1 child with special needs	6 (35.3%)	4 (17.4%)	7 (15.9%)	6 (17.6%)	0 (0%)	2 (9.5%)

Coping style, health status and family well-being

Research Questions: *Is there a relationship between family well-being and primary parent-carer coping style? Do family well-being groups differ on primary parent-carer coping style?*

A significant correlation between family well-being and *Non-productive Coping* was found at I1 (r=-.28, p<.05) and I2 (r=-.23, p<.05). Family well-being scores tended to be lower in families where primary parent-carers more frequently used *Non-productive Coping* strategies such as worrying, self-blame, consciously 'blocking out' the problem, or getting sick. No significant correlation was found between family well-being and using *Dealing with the Problem, Optimism* and *Sharing* coping styles.

Employing regression analysis, use of *Non-productive Coping* strategies was found to be a significant predictor of family well-being at both I1 (F=7.9, p<.01) and I2 (F=7.9, p<.01), accounting for 10% and 12% of the observed variance respectively.

Differences between well-being groups in the frequency of use of coping styles were examined using One-way ANOVA with Bonferroni contrasts. No statistically significant between group differences were found at I1. At I2 there was one significant difference with primary parent-carers in Struggling families using *Optimism* more frequently (F=4.2, p<.05). *Optimism* includes strategies such as praying for help and guidance, looking on the bright side of things, daydreaming about how things will turn out well and making time for leisure activities. This finding suggests that primary parent-carers in Struggling families feel that there is not much they can do to change their situation.

Research questions: *Is there a relationship between family well-being and primary parent-carer health? Do family well-being groups differ on primary parent-carer health? Do family well-being groups differ on primary parent-carer health compared to population norms?*

Family well-being and primary parent-carer health status were highly correlated. Pearson correlation coefficients were significant (p<.05) for all SF36 subscales as well as the physical and mental health component summary scales at I1, ranging from r=0.24 for Physical Functioning through to r=0.52 for Mental Health. Correlations between family well-being and SF36 subscale scores at I2 were significant (p<.05) for the Mental Health subscale (r=.32) and the Mental Health Component summary scale (r=.28).

Mean (and standard error of the mean) SF36 subscale scores for the Australian population and family well-being groups at I1 are shown in Table 10.   Between group comparisons on I1 data using One-Way ANOVA revealed statistically significant differences in health status on seven of eight SF36 subscales (excluding Physical Functioning) and on both physical and mental health component summary scales. Between group comparisons on I2 data using One-Way Anova revealed significant between group differences on the Mental Health subscale only.

Bonferroni contrasts were computed using I1 data to examine between group differences at p< .05. Primary parent-carers in Thriving families reported significantly better Mental Health than those in both other groups. Furthermore, these primary parent-carers also reported better health than those in Struggling families on a further six subscales: Role Physical, Bodily Pain, General Health, Vitality, Social Functioning and Role Emotional. Primary parent-carers in Struggling families fared significantly worse than primary parent-carers in both other groups on the Physical and Mental Health component summary scales.

Employing multiple regression analysis, all of the eight SF36 sub-scales and two component summary scores were found to be significant predictors of family well-being at I1 (F=5.3, p<.001), explaining 40% of the observed variance.   However, inspection of T-values showed that only the Mental Health sub-scale made a significant contribution to the prediction of family well-being (t=2.6, p<.05).   In other words, the correlation between the Mental Health subscale and other SF36 variables is such that the latter's contribution to the prediction of family well-being is mostly subsumed by the Mental Health subscale.

Figures 2 and 3 illustrate the health disparities between family well-being groups and Australian SF36 norms at I1 and I2 respectively. Primary parent-carers in Thriving families have the best health status and those in Struggling families tend to have the poorest. Primary parent-carers in each family well-being group have significantly poorer Mental Health and Vitality compared with Australian norms. However, on the Physical Component summary scale, the Doing OK and Thriving groups reported significantly better health than the Australian norm.

Table 10: Health status at I1 and Australian norms

	Australian norms	Struggling I1 (n=17)	Doing OK I1 (n=44)	Thriving I1 (n=20)
Physical Functioning	82.5	74.4 (5.9)	85.1 (2.7)	88.0 (3.8)
Role Limit Physical	79.8	48.4 (10.3)*	69.6 (5.8)	85.0 (5.3)
Bodily Pain	76.8	63.9 (5.8)	70.8 (3.6)	85.6 (3.1)#
General Health	71.6	61.0 (5.1)	72.1 (2.8)	81.1 (3.3)#
Vitality	64.5	38.1 (6.2)*	50.5 (2.8)*	55.5 (3.4)*
Social Functioning	84.9	60.0 (5.9)*	74.4 (3.4)*	83.8 (4.4)
Role Limit Emotional	82.8	33.3 (11.0)*	61.9 (6.4)*	75.0 (7.6)
Mental Health	75.9	42.7 (3.9)*	52.3 (2.5)*	66.8 (1.7)*
Physical Component Score	49.1	47.7 (2.1)	53.4 (1.3)#	56.3 (1.4)#
Mental Component Score	50.1	30.7 (3.4)*	39.5 (1.8)*	45.0 (1.6)*

*indicates significantly *(p<.05)* poorer health compared to Australian norms

# indicates significantly *(p<.05)* better health compared to Australian norms

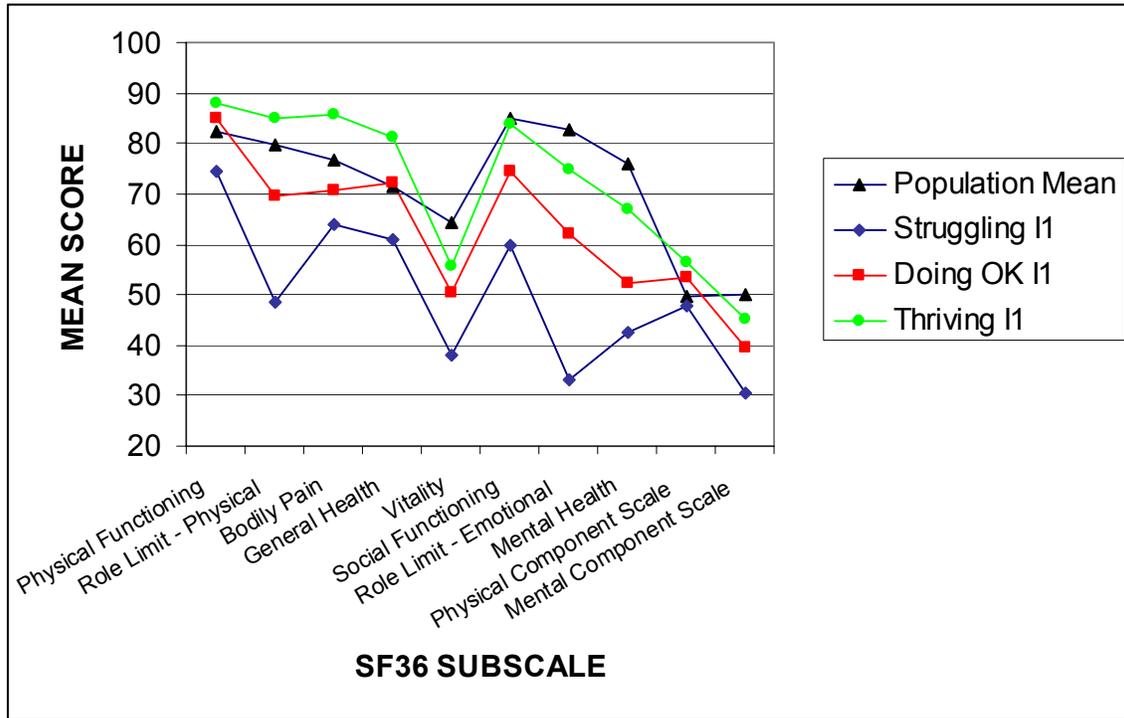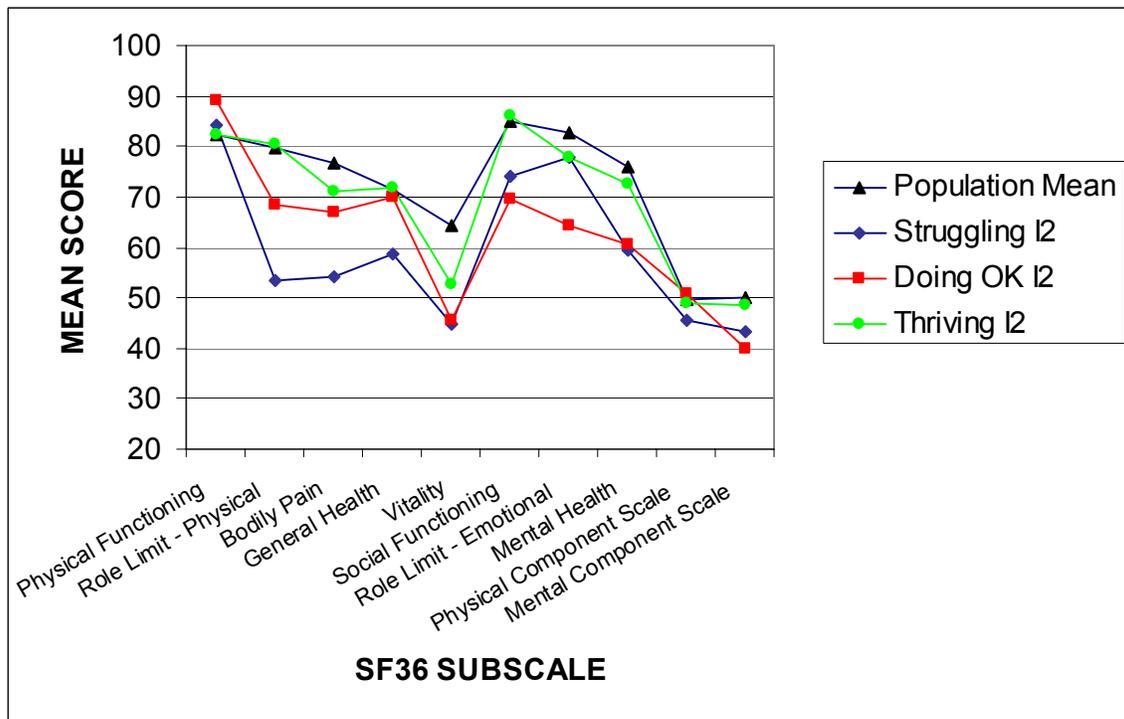**Figure 2: Health status at I1 and Australian norms**

Figure 3: Health status at I2 and Australian norms

Research question: Is Non-productive Coping a significant predictor of family well-being after controlling for primary parent-carer mental health?

Hierarchical regression analysis was used to examine the contribution of primary parent-carer mental health and use of *Non-productive Coping* to predicting family well-being, and to determine if *Non-productive Coping* was a significant predictor after controlling for the SF36 Mental Health sub-scale score. Together mental health and *Non-productive Coping* explained a significant 26% of the variance at I1 (F=12.2, p<.01) and 10% of the variance at I2 (F=3.4, p<.05). However, at both I1 and I2, inspection of significant T-values showed that *Non-productive Coping* ceased to be a significant predictor after controlling for mental health. One possible explanation is that the effect of *Non-productive Coping* strategies on family well-being is mediated by primary parent-carer mental health.

Ecocultural dimensions and family well-being

Research question: Which aspects of the families' everyday lives are associated with family well-being?

Analysis of the data from the Ecocultural Family Interview involved several steps to identify which variables best explain the variance in family well-being. *As a first step*, we examined the internal consistency of the ecocultural items categorised *a priori* by Gallimore and colleagues (Ecocultural Scale Project, 1997c) into 10 conceptual domains. Low Cronbach alpha coefficients indicated eight of the ten domains had little internal consistency with only Socio-economic Status and Family Connectedness having alpha coefficients greater than 0.6. Llewellyn et al. (1999) reported similar poor internal consistency in the original 10-ecocultural domains. In that case, the authors continued by undertaking a factor analysis. In the current study factor analysis was not appropriate given the low ratio of cases to items. Low internal consistency of the original domains in both studies may be an artefact of using the Ecocultural Family Interview with families of children with disabilities and high support needs in contrast to families in the original study (Ecocultural Scale Project, 1997c) with families of children with undiagnosed developmental delay.

The second step therefore involved reassigning the ecocultural items (48 in total) to seven dimensions based on conceptual analysis of the interview data. Each of the seven dimensions demonstrated acceptable internal consistency with Cronbach alpha coefficients greater than 0.7 at I1. The alpha coefficients for five of the seven dimensions were higher at I2 confirming reliability of the conceptual reordering of items into dimensions. The seven dimensions, corresponding items and Cronbach alpha coefficients are shown in Table 11.

The next step involved multiple regression analysis to determine to what extent the items in each dimension together predicted family well-being and to identify which items had significant T-values. Table 12 lists the R^2 value for each dimension, that is, the proportion of variance explained, and the items in each dimension with significant T-values.

Table 11: Ecocultural dimensions of family life

Dimensions	Alpha I1	Alpha I2	Description	Items
Sharing Workload & Responsibility	.79	.67	Positive family affect and shared participation in activities and decision-making.	* Connected family (i.e. close-knit family) * Overall agreement and consistency between parents regarding childcare, household tasks, acceptance of the child and child status * Parents/couple have grown closer because of the child * Flexibility of partner's/spouse's work or study schedule * Time availability of partner/spouse for the child * Partner's/spouse's participation in childcare and domestic tasks and activities. * Amount of help the primary parent-carer receives with childcare from his/her spouse/partner, the child's siblings or others living in the home * Amount of help the primary parent-carer receives with childcare from non-relatives or relatives living outside the home * Amount of help the primary parent-carer receives with domestic workload from his/her spouse/partner, the child's siblings or others living in the home * Amount of help the primary parent-carer receives with the domestic workload from nonrelatives or relatives living outside the home * Family reliance on help from kin, including for example the child's aunts and uncles, or grandparents * Participation/involvement of siblings in looking after and/or looking out for the child.

Dimensions	Alpha I1	Alpha I2	Description	Items
Balancing Needs and Demands	.74	.77	Challenge of meeting care demands and balancing the needs of different family members	* Evidence that the primary parent-carer believes the child is an opportunity or positive development rather than a burden or bad luck * How difficult is it to care for this child? * Family arranges time or schedules around the child * Level of family activity currently focused on arranging and sustaining childcare for the child * Complexity/elaborateness of the primary parent-carer's childcare workload and schedule * Complexity of primary parent-carer's domestic workload and schedule * Flexibility of primary parent-carer's current workload or study schedule * Time availability of the primary parent-carer for the child * Overall childcare workload related to the child's siblings * Differential treatment of child compared to his or her siblings related primarily to the child's disability * Current issues, concerns, and problems regarding child care responsibilities of the siblings * Issues, concerns, and problems regarding future responsibilities of siblings * Evidence that family believes the child needs protection due to sexual development

Dimensions	Alpha I1	Alpha I2	Description	Items
Integrating the Child	.73	.77	Family beliefs and activity related to the integration of the child into the typical, everyday world	* Evidence that the family's goal is for the child to be integrated into the typical, everyday world * Current extent to which the child is integrated into the typical, everyday world * Level of family activity currently focused on the child's interaction with non-disabled peers * Involvement of either or both parents in the child's school and classroom activities * Family works on a daily basis on school-work * Safety of the neighbourhood for children appropriate to the age of the child * Recent evidence that parents believe that the child needs protection from failure, ostracism and/or negative social attitudes * Overall involvement of child in disability groups/activities recently or in the recent past * Current family involvement with child disability organisations and groups

Dimensions	Alpha I1	Alpha I2	Description	Items
Accessing Special Services	.70	.72	Activity focused on accessing information and special services related to the child's diagnosis and functioning, and the effect on the parents' work arrangements and career decisions	* Level of family activity focused on getting and using special services for the child * Amount of contact with health professionals, hospitals, etc, excluding schools related to the child * Amount of parent actions in relation to their child's diagnosis and present level of functioning * Level of family activity currently focused on accessing sources of information to help the child * Amount of information recently received from professionals regarding child's diagnosis and/or level of functioning * Effect of child on the mother's work arrangements and career decisions * Effect of child on the father's work arrangements and career decisions
Financial Resources	.89	.89	Adequacy of finances and affordability of desired services	* Overall resilience of subsistence base * Overall satisfaction with subsistence base * Can family afford all the services they want for their child
Home and Neighbourhood	-.99	-.59	Suitability of the home, and use of neighbourhood places and services	* Level of family activity currently focused on constructing or changing home and yard for benefit, convenience or safety of the child * Use of neighbourhood places and services appropriate to the age of the child
Spiritual Beliefs and Affiliation	.78	.81	Importance of spirituality, and any meaning it gives to having a child with a disability	* Current parental commitment to religion, spirituality, and worship * Religion currently gives meaning to having a child with a disability

Table 12: Ecocultural item predictors of family well-being

Dimensions	Items with significant T-values	I1 R^2	I2 R^2
Sharing Workload and Responsibility	*Connectedness of the family (I1 & I2)* *Parents have grown closer because of the child (I1)* *Flexibility of father's work/study schedules (I1)*	.55	.40
Balancing Needs and Demands	*Child viewed as burden or opportunity (I1, I2)* *How difficult is it to care for the child? (I1, I2)* *Overall childcare load related to siblings (I2)*	.71	.84
Integrating the Child	*Evidence that family's goal is for the child to be integrated into the typical, everyday world (I1, I2)* *Safety of the neighbourhood for the child (I2)*	.39	.47
Accessing Special Services	*Information recently received from professionals re child diagnosis or functioning (I1, I2)* *Effect of child on mother's work arrangements and career decisions (I1, I2)*	.27	.26
Financial Resources	*Satisfaction with subsistence base (I1, I2)* *Affordability of desired services (I1)*	.37	.35
Home & Neighbourhood	*Family activity focused on constructing or changing home and yard for benefit, convenience or safety of the child (I1, I2)* *Use of neighbourhood places and services appropriate to the age of the child (I1, I2)*	.29	.26
Spiritual Beliefs and Affiliation		.02	.00

Six of the seven dimensions were significant predictors of family-well-being at both I1 and I2. These are:

- Sharing Workload and Responsibility (I1 F=6.9, p<.001; I2 F=2.9, p<.005)
- Balancing Needs and Demands (I1 F=11.9, p<.001; I2 F=19.3, p<.001)
- Integrating the Child (I1 F=4.8, p<.001;I2 F=6.1, p<.001)
- Accessing Special Services (I1 F=3.9, p<.005; I2 F=3.1, p<.01)
- Financial Resources (I1 F=15.1, p<.001; I2 F=13.0, p<.001)
- Home and Neighbourhood (I1 F=15.9, p<.001; I2 F=13.2, p<.001).

The dimension of *Balancing Needs and Demands* was the strongest consistent predictor of family well-being. No significant relationship was found between family well-being and Spiritual Beliefs and Affiliation.

The final step involved multiple regression analysis with all significant predictor ecocultural items entered in a single step. At I1, these items together explained a significant 86% of the variance in family-well-being (F=35.4, p<.001). At I2, these items accounted for a significant 84% of the variance in family well-being (F=25.2, p<.001). These seven key ecocultural items are:

⬧ Connected (i.e. close-knit) family *(I1, I2)*

⬧ How difficult is it to care for the child? *(I1, I2)*

⬧ Child is viewed as an opportunity or positive development rather than a burden or bad luck *(I1, I2)*

⬧ Family activity focused on changing the home/yard environment for benefit of the child *(I1)*

⬧ Overall satisfaction with subsistence base *(I1, I2)*

⬧ Effect of child on mother's work arrangements/career decisions *(I1)*

⬧ Family goal for the child to be integrated into the typical, everyday world *(I1)*

The findings indicate that the contributions made by the ecocultural items listed in Table 12 are subsumed by these seven key variables. Figures 4 and 5 show the near monotonic relationship between these key ecocultural predictor items and family well-being groups at I1 and I2 respectively.

Figure 4: Family well-being and key ecocultural predictor items at I1

WELLBEING GROUP I1

Legend:
- efi2 - Satisfaction with subsistence bas
- efi18 - How difficult is it to care for
- efi32 - Connectedness of the family
- efi35 - Child is viewed as a burden
- efi4 - effect of child on mo's career an
- efi13 - Family activity focused on home
- efi41 - goal tha child is integrated int
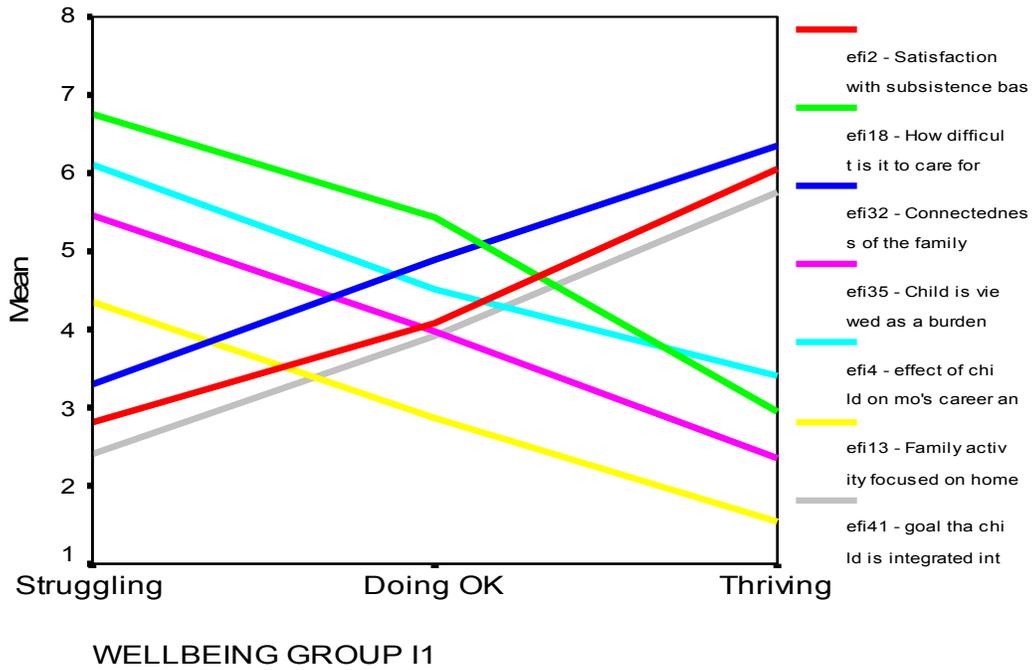
Figure 5: Family well-being and key ecocultural predictor items at I2

WELLBEING GROUP I2

Legend:
- 2efi2 - Satisfaction with subsistence ba
- 2efi18 - Difficulty caring for the child
- 2efi32 - Connectedness of the family
- 2efi35 - Child viewed as burden
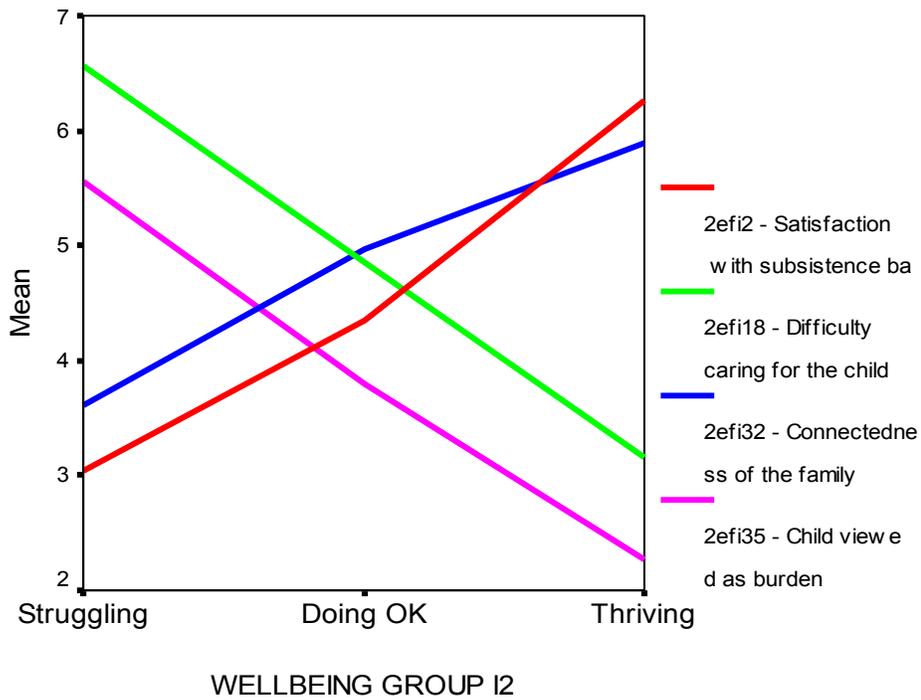
Family well-being and child health and hassle

Research questions: Is there a relationship between family well-being and the demands placed on the family as measured by the Child Health and Hassle Scale? Do the family well-being groups differ on the demands placed on the family as measured by the Child Health and Hassle Scale?

There was a significant (p<.05) correlation between family well-being scores and all seven dimensions of the Child Health and Hassle Scale at both I1 and I2. The Pearson correlation coefficients ranged from r=-0.26 (Responsiveness) to r=-0.48 (Global Hassle) at I1 and from r=-0.29 (Medical/health care) to r=-54 (Global Hassle) at I2.

Figures 6 and 7 show the differences between family well-being groups on each Child Health and Hassle subscale at I1 and I2 respectively. One-Way ANOVA revealed significant between group differences on six of seven subscales (excluding Responsiveness) at I1 and all seven subscales at I2. With Bonferroni contrasts, the analysis revealed that all three groups differed significantly (p<.05) from one another on the Interaction subscale at I1 and the Global Hassle subscale at I2. Thriving families were distinguished from both other groups (who did not differ) on Aberrant behaviours (I1), Appropriacy (I1) and Global Hassle (I1). Struggling families differed from both other groups (who did not differ) on Interaction (I2). On all other measures, with the exception of medical/health care (I1), the significant difference lay between Thriving and Struggling families.

Figure 6: Well-being groups and Child Health and Hassle at I1
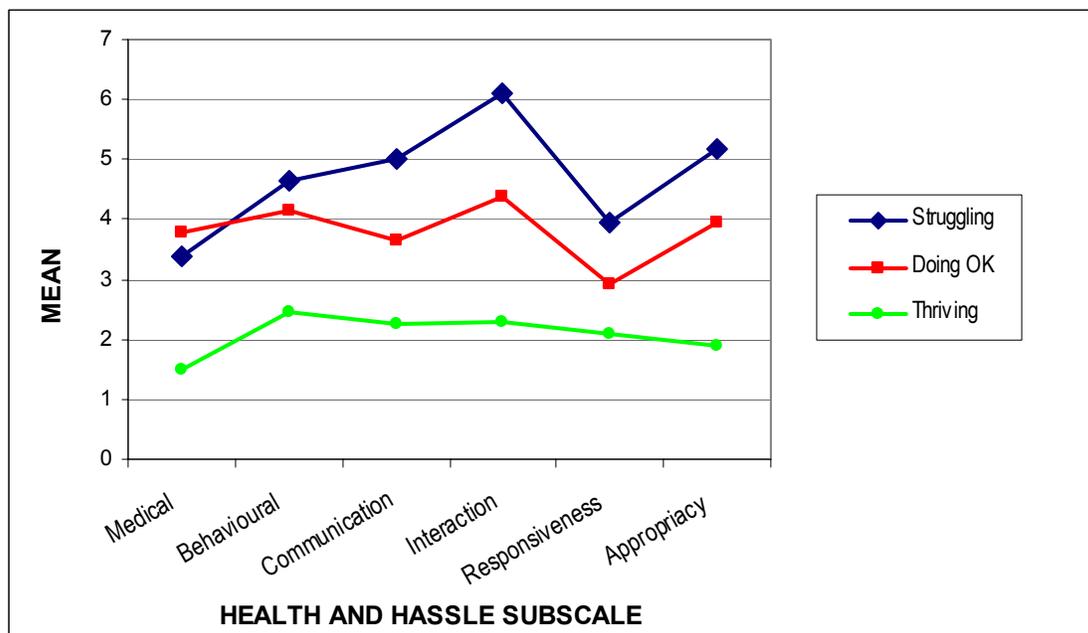
Figure 7: Well-being groups and Child Health and Hassle at I2
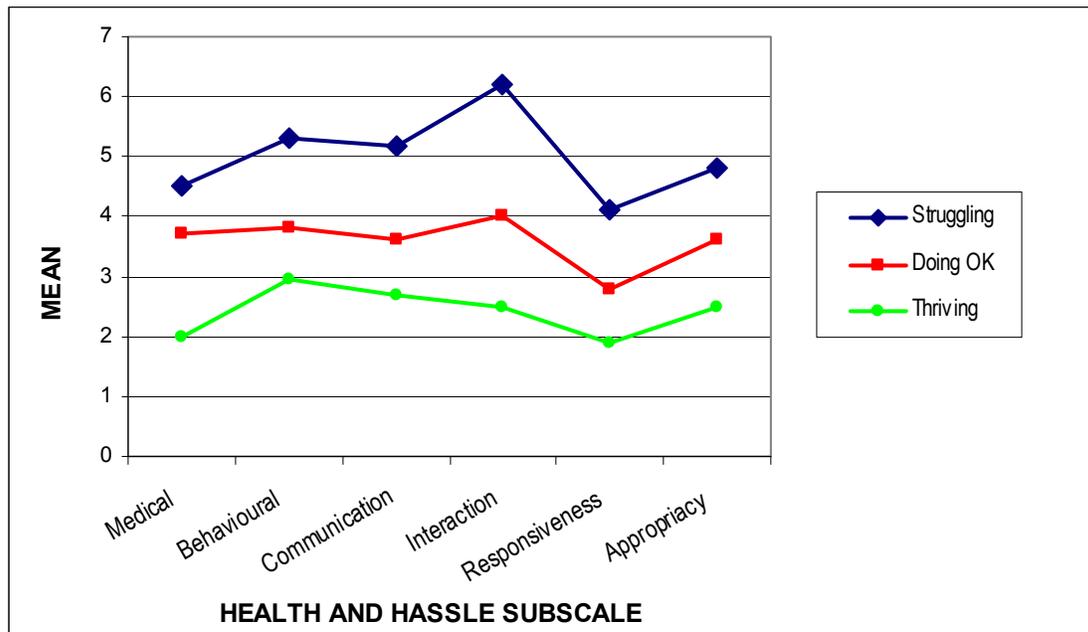
Change in family well-being

Research question: Which aspects of everyday family life are associated with change in family well-being?

Over one-third (n=28, 35.9%) of families experienced a change in their family well-being to the extent that they had changed groups by the time of the second interview. Twelve families (15.4%) experienced an *up-turn in family well-being*. Of these twelve, 5 (29%) families in the Struggling group moved into the Doing OK group and 7 (17%) families in the Doing OK group moved into the Thriving group.

Sixteen families (20.5%) experienced a *down-turn in family well-being*. Of these sixteen, 5 (25%) families in the Thriving group moved into the Doing OK group, 10 (24%) of the Doing OK group joined the Struggling group and one family in the Thriving group experienced such a decline in their family well-being that they became members of the Struggling group. These changes are represented graphically in Figure 8.

Figure 8: Changes in family well-being I1 and I2

Struggling families	Doing OK	Thriving	Total
Upturn			
5 (29%) ───────→	7(17%) ──────────→		12
Downturn			
←───────────	10 (24%) ←───────	5 (25%)	16
←────────────────────────		1 (.05%)	

Most of the changes (61%) occurred for families in the Doing OK group. The family well-being scores of almost one-half of this group (42%) changed. The family well-being of families in the other two groups was relatively stable with no change in nearly three-quarters of families. Fourteen families (70%) of the Thriving group and twelve families (71%) of the Struggling group remained in their respective groups at I2.

Although on average families in the Struggling group fared worse at the time of the second interview (-.7) and the other two groups improved (1.05 for the Doing OK group and 1.4 for the Thriving group), there was no significant difference between the groups in terms of mean change in family well-being from I1 to I2.

Hierarchical regression analysis was employed to determine whether primary parent-carer Mental Health status, use of *Non-productive Coping* strategies, and Global Child Hassle at I1 predicted family well-being at I2 (12-15 months later), after controlling for family well-being at I1. Family well-being at I1 explained a significant 58% of the variance in family well-being at I2 (F=93.4, p<.001). Measures of primary parent-carer Mental Health, use of *Non-productive Coping* strategies, and Global Child Hassle at I1 did not improve the prediction significantly.

The seven key ecocultural items at I1 (listed above) were then entered into a multiple regression analysis to determine how well these together predicted family well-being at I2. These variables explained a significant 59% of the variance in family well-being at I2. However, only three key ecocultural items had significant T-values (p<.05). These were:

* Overall satisfaction with subsistence base

* Child is viewed as an opportunity or positive development rather than a burden or bad luck

* How difficult is it to care for the child?

In short, consideration of these three items at I1 alone gave a good indication of how well families were doing (that is, their family well-being) approximately one year later.

To complement the statistical analyses, a qualitative analysis of the interview transcripts for the 28 families who changed well-being groups from I1 to I2 was undertaken. This analysis focused on identifying circumstances associated with change in family well-being. The circumstances described below rarely occurred in isolation and were often inter-related or sequential. These findings suggest the need to focus not only on single events in family life but also on clusters of events and potential chain-like effects leading to a change in family well-being.

Up-turn in family well-being

Changes in workforce participation and/or family subsistence base were prominent features. For some parents, particularly mothers, increasing their hours of paid employment, being promoted or changing employment resulted in increased family income. Self-employed parents benefited financially from an up-turn in the family business. Increased income enabled several families to make home modifications (e.g. bathrooms), move to a more "convenient for caring" house, and/or purchase services (e.g. home help), which in turn, lightened the physical care load associated with their child with a disability and high support needs.

For some mothers, a change in work arrangements brought other benefits. One mother talked about how she now had an "outlet" other than her children and that work gave her the opportunity to get out of the house. Another mother's changed work arrangements gave her greater flexibility to work from home and to "be home for the children in the afternoon".

A key point is that family well-being surged only when changes in work arrangements or workforce participation were in keeping with family goals/values/beliefs. Another key point is that changed work arrangements have varying benefits for individual families. For example, one family may benefit from a reduction in the physical care workload (e.g. through home modifications or purchase of services) while another may benefit from greater flexibility (e.g. working from home) and/or personal fulfilment.

Increasing satisfaction with their child's school placement/experience and overall progress also featured in families experiencing an up-turn in their family well-being. Several families had 'fought for' and achieved "more integration" for their child at school and observed that their child "seemed to be progressing much better". For other families

a new teacher and improved communication between home and school made the difference. Achieving special class placement increased some families' satisfaction. Integration (or more integration) therefore was not every family's goal. For example, one mother was looking forward to her child's imminent placement in a special class—she believed that this would be better for her son who 'stood-out' in the mainstream class. Another mother - after a long wait - had obtained a place for her son at a special residential school for five days and four nights per week. This mother noted, "life is a whole lot less stressful now". She was very pleased with the school and was now able to take up paid employment. The significant feature is not the change in school placement *per se* but rather the fulfilment of the family goals in relation to their child's schooling.

Extra help and time-out from caregiving was another feature of families who experienced improved well-being. For quite a few families, the extra help came from extended family members or increased support networks such as reciprocal supervision (baby-sitting) arrangements with neighbours who "watch out for one another's kids". For example, one mother was now receiving a great deal of help with childcare and home tasks from her sister who had recently arrived in Australia. Her sister's support also allowed her to take time-out including a weekend away with her husband. Another mother acknowledged her neighbour who was "always keen to care for her" daughter and this gave this mother some quality time with her other children.

Extra help and time-out from caregiving also came in the form of changes in services. Some families were now able to purchase services such as a 'nanny' or a house-keeper and these services were ones over which they had more control. One financially secure family had decided to do away with all formal services, which "tended to cause more worry than satisfaction". Other families benefited from improved service arrangements such as more regular and consistent Home Care workers. Another mother had learned a great deal from a parent education group with a focus on child behaviour management strategies; her experience was so positive that she was planning to attend again in coming weeks.

The extra help that many parents received from sources outside the service system highlighted the importance of extended family support and positive relationships with neighbours. Many benefits flowed from extra help being provided over and above the reduction in childcare workload. For example, by having more time to spend with partners and other children, primary parent-carers could ensure that no family member was "missing out". As one mother put it, "my daughter is just a part of the family and they all fit in with each other".

Up-turn in family well-being also came about when particular stressors were removed. For some families this occurred when, for example, medication was finally sorted out after months of 'experimenting', or the family were able to move from unsuitable accommodation (on the first floor), or daily routines had been simplified, for example, by having only one after school care arrangement rather than multi-care arrangements.

For some mothers, it was neither stability of family routines nor removal of stressors that occasioned an up-turn in family well-being. Instead these mothers talked about coming to a different level of acceptance about their family situation. There was no obvious change in their family routines however the mothers had come to view their family life quite differently. For others, taking on employment for the first time or returning to a previously amenable workplace provided that "something for myself" which changed the perspective on their family lives.

Down-turn in family well-being

Significant change in daily family routine was the prominent feature in the lives of the families experiencing a down-turn in their family well-being. Changes included hospitalisation of the child for surgery, the onset of complicating medical conditions (such as epilepsy), and/or the emergence of (more) challenging behaviours. Increasing care demands and uncertainty about the present and future for their child with a disability and high support needs or their family were dominant themes.

For many families, the increased care demands necessitated a change in work arrangements or workforce participation as one or both parents needed to be with their child all the time. A substantial reduction in family income was usually the result. One family had to postpone much needed renovations that would have made caring a whole lot easier. Loss of income was compounded by increased social isolation and loss of quality family time. One mother explained that her family could no longer go out together because her daughter, in plaster after surgery, required constant monitoring "to make sure she didn't fall". Another mother stopped visiting her friends through the day because of her child's behaviour problems; she said, "I am never sure what he is going to do".

The help available to many families had also dried up. There were varying reasons for this. Some families, concerned about their child's extra-special needs and vulnerability, would no longer 'entrust' others with his or her care. Other parents were keen for a break but were unable to find any service willing to provide this. In one instance, a mother explored the possibility of vacation care but was informed that her child's special needs

could not be accommodated. Several families had moved away from their support network or conversely those supporting them had moved away. In short, these families had to meet additional care demands and do so with less help from others.

The emergence of more challenging behaviours or complicating medical conditions dashed some parents' hopes with regard to their child's progress. One mother was very upset because she had expected her child to become more independent and he was, in fact, more dependent than ever. For some, relationships between family members had become strained. A few parents observed that the child's behaviour problems created friction with siblings. In one case a mother was concerned that the child's siblings were rejecting her by refusing to learn the sign language she used.

Not surprisingly, most of these mothers were now experiencing overwhelming fatigue. One mother had recently been in hospital herself, which she attributed to the stress of looking after her son. Another mother had been ill with the suspected return of an earlier cancer but was reluctant to investigate further until her son had fully recovered from his surgery. Most of these mothers associated their fatigue with the accumulated demands of caring for their child through difficult times, taking sole responsibility for managing family affairs, and working to support their families financially. Several mothers regretted receiving little help from their husbands or other family members. For some it was the responsibility not the workload that weighed heaviest; having to make all the decisions on their own was a significant strain.

Uncertainty about the present and/or the future dogged the daily lives of primary parent-carers experiencing a down-turn in their family well-being. Some were concerned about their living conditions. Would their house be suitable in the future? Could they afford to move to a more suitable house? and so on. Others were concerned about their child's school placement. Was special class the best option? Ought they to consider integration or perhaps even special school? Several parents also expressed their concern about neglecting their other children. For example, one mother said her son was demanding a lot more attention and she was feeling guilty about not paying sufficient attention to the others. Another mother expressed concerns about the unrest in her household, as the other children were getting older and needed to study more. Others were concerned about their child's future. Where would they live? Would a suitable placement be available when it was needed? Overall, disruption to, and uncertainty about everyday family routines were at the core of experiencing a downturn in family well-being.

FINDINGS AT A GLANCE

⬥ For the purposes of this study, family well-being was defined as the extent to which there is a meaningful, congruent and sustainable family routine. Based on family well-being scores, the largest proportion in this sample was the group of families who were Doing OK (I1, 54.3%; I2, 43.6%). Around one quarter of the sample of families were in the Thriving group (24.7% at I1, 26.9% at I2) and the remaining approximately one-quarter of families were in the 'Struggling' group I1, 21% and I2, 26.9%).

⬥ The three groups of families differed on a number of demographic variables. ***Families in the Thriving group*** exhibit the following demographic characteristics: two parent households, higher family incomes and full integration of their child with disabilities into a mainstream school. These three variables alone explain a significant 25% of the variance in family well-being at I1 ($F=8.6$, $p<.001$) and 28% of the variance at I2 ($F=9.6$, $p<.001$), computed using regression analysis with all variables entered in a single step. These demographic features could be described as an *advantage* profile of family well-being. ***Families in the Struggling group*** exhibit the following demographic characteristics: sole parent households, relatively low family incomes, more than one child with special needs, special schooling and relatively frequent use of respite care. These five variables alone explain a significant 36% of the variance in family well-being at I1 ($F6.6$, $p<.001$), and 31% of the variance at I2 ($F=5.2$, $p<.001$), computed using regression analysis with all variables entered in a single step. These demographic features could be described as a *risk profile* of family well-being.

⬥ Primary parent-carers in the three groups differed in terms of their health. Primary parent-carers in the Struggling group fared significantly worse than primary parent-carers in both other groups in terms of their physical and mental health. They also perceived more demands in terms of their child's medical/health care needs and behaviours than did those in the Thriving group. Notwithstanding primary parent-carers in all three family well-being groups had significantly poorer mental health and vitality (as measured by the SF-36) by comparison with Australian norms.

⬥ Seven key ecocultural items were associated with family well-being. These are:

◊ Connected (i.e. close-knit) family

◊ How difficult is it to care for the child?

◊ Child is viewed as an opportunity or positive development rather than a burden or bad luck

◊ Family activity focused on changing the home/yard environment for benefit of the child

◊   Overall satisfaction with subsistence base

◊   Effect of child on mother's work arrangements/career decisions

◊   Family goal for the child to be integrated into the typical, everyday world

◆ Family well-being is subject to change depending on circumstances and driven by events which disrupt or destabilize everyday family routines. Single events, a cluster of events or a chain-like sequence that unsettle family routines can all result in family well-being changing for the better, or for the worse. The three key ecocultural items that best predict such change are: overall satisfaction with subsistence base, child is viewed as an opportunity or positive development rather than a burden or bad luck, and the difficulty caring for the child.

Out-of-home Placement

Contents

Aim

To identify factors associated with out-of-home placement tendency among families with children with disabilities and high support needs aged 6-13 years.

Objectives

- To determine the extent to which families with children with disabilities and high support needs consider out-of-home placement

- To examine the relationship between family well-being and out-of-home placement tendency

- To identify factors that help explain variation in out-of-home placement tendency

- To describe those families who moved closer to out-of-home placement during the study period

Measuring out-of-home placement tendency

Out of home placement tendency was examined using the Placement Tendency Index (Blacher, 1990) on which the primary parent-carer rates her/his current thinking about placement. This is done using a six-point scale that ranges from never having considered placement to having taken all steps to place the child. Primary parent-carers subsequently provide an explanation for their rating.

The following includes the descriptors for each point on the scale, a short quote to illustrate these and a brief description of the rationale provided by caregivers for assigning themselves to a particular point on the scale.

1. *No, we have never considered placement as an option for our child.*
   "When he is ready and older, he can leave if he wants to…"

   Generally primary parent-carers talk about caring for their child indefinitely unless something 'unimaginable' happens or the child choses to move out of home as an adult.

2. *Occasionally the subject of placement comes up, but we do not seriously consider it.*
   "I am still able to look after him…"

   Primary parent-carers can imagine that placement might be necessary some time in the future but feel unable to discuss this as an option at present. They may also have had an issue in the past that made them consider placement as an option but this issue is now resolved.

3. *Yes, we have thought about it a lot, but have done nothing*
   "Coming to the realisation…"

   Primary parent-carers describe coming to the realisation that placement is an emotionally acceptable and practical option for the future. Families may have placed their child's name on the government placement database at the recommendation of professionals.

4. *We have inquired about placement, visited residences, but done nothing else.*
   "We really need to think about it for the future…"

   Primary parent-carers have made enquiries, visited places and begun asking questions in earnest about placement for some time in the future though exactly when remains vague. They often begin visiting places on advice from professionals to get on the waiting list for specific out-of-home placement services.

5. *We have taken steps to place our child. The paper work is in progress.*
   "Some time soon…"

   Primary parent-carers have selected placement options, completed application form(s) and are on one or more waiting lists. They expect the child to be living out of home some time within the next one to three years but accept that they will (have to) take placement as soon as it becomes available.

6. *We have made all arrangements. The child is placed or awaiting immediate placement*
   "As soon as possible" or "child already living out of home"

   Primary parent-carers have placed their child out of home or are anxiously awaiting an already agreed and planned out-of-home placement to become available.

Out-of-home placement tendency findings

Most families had never considered or were not seriously considering out-of-home placement at I1 and I2. The frequency counts and percentages are shown in Table 13. However the number of families who had made enquiries, taken steps to place or who had made all the arrangements more than doubled between I1 (n=5, 6.2%) and I2 (n=14, 17.9%). Indeed, on average, placement tendency increased during the study period. Employing a paired samples T-test, the mean placement tendency index scores at I1 (mean=1.58) and I2 (mean=2) were found to be significantly different (t=-4.1, p<.001).

Table 13: Out-of-home placement tendency

Placement Tendency	Score	Interview 1 n=81	Interview 2 n=78
Never considered placement	*1*	55 (67.9%)	45 (57.7%)
Have not seriously considered it	*2*	16 (19.8%)	12 (15.4%)
Thought about it a lot, but done nothing	*3*	5 (6.2%)	7 (9.0%)
Have made enquiries	*4*	3 (3.7%)	7 (9.0%)
Have taken steps to place	*5*	0	4 (5.1%)
All the arrangements have been made	*6*	2 (2.5%)	3 (3.8%)

Three groups were created based on Placement Tendency Index scores. These groups were: *Never considered* (score of 1), *Considered placement* (score of 2 or 3), and *Taken action toward placement* (score of 4-6). The number of families and percentages in each group at I1 and I2 are shown in Table 14.

Table 14: Placement tendency re-grouped

	I1	I2
Never considered placement	n=55 (67.9%)	n=45 (57.7%)
Considered placement	n=21 (25.9%)	n=19 (24.3%)
Taken action toward placement	n=5 (6.2%)	n=14 (17.9%)

The following descriptions of each of the three groups were derived from qualitative analysis of interview data.

Never considered placement

Those families that had never considered or were not seriously considering placement had difficulty imagining a time when they would not care for their child with a disability.

These families felt that as their children were young they were quite able to meet their needs. Their own "good health" and "ability to cope" were frequently given as reasons for not considering placement. Attitudes were also important reasons given by these caregivers. These were expressed in comments such as "my child, my responsibility," "an integral part of their family unit", and "challenge chosen for us". The overall connectedness of the family unit, the place of the child with a disability within the family, and the informal and formal support available were also mentioned. Some may have given placement a passing thought particularly when confronted with an acute issue such as child or parent health concerns but this had always been dismissed as not an option for their family.

The reasons given for adopting the caring role by primary parent-carers in this group are similar to those reported more generally by carers, namely, family responsibility (48%), belief that they could provide better care (48%), and/or an emotional obligation (40%) (Australian Bureau of Statistics, 2001).

Considered placement

In contrast, families who had considered placement could envisage a time in the future when they would not be able to care for their child. This was most frequently because of their health. These families had begun making enquiries to ensure placement was available when they needed it.

Advice from professionals "to get into the system" to make sure of a place in the future was by far the most frequently mentioned reason underpinning their considerations. Perceived limited placement options for young adults with high support needs meant that families were beginning to act now to avoid full time care at home when their child had finished school. Other reasons included: the potentially detrimental effect of the child with disabilities on siblings (e.g., less attention from parents, increased caregiving responsibilities); declining caregiver health; limited respite (both formal and informal); increased child size and/or behaviour problems; and, a desire for life outside of that of a caregiver (e.g., return to paid employment).

One mother speaks for many with these words: "I hope we will still be able to look after her, but we will need a lot of help to do that, you know, so that she would still be able to be a part of this home, because she always has been. I personally couldn't put her away, you know, like have her away from me more often than not. But you know, maybe that is just something that I need to get used to, and probably, over time, I guess I would get used to that".

Taken action toward placement

Families in this group had resolved to place their child out of home in the immediate or near future (within 2 years) and had made all the arrangements. These families fell into two sub-groups. The first were families currently experiencing some or all of the factors mentioned as possible future concerns by the families considering placement (the previous group) such as poor caregiver health, feeling worn out, unacceptable caregiving responsibilities for siblings, and so on.

The second were families for whom, regardless of their readiness to place their child, a place had become available or was likely to be available in the near future. These families felt pressured to accept placement when this was offered because they were afraid that if they did not take this now it would not be offered again. Single parents were over-represented in this sub-group. A lack of practical and emotional support from another adult (or spouse) was frequently given as the reason for having resolved to place their child. In addition, the possibility that something (e.g., injury, poor health) might leave them unable to care for their child frequently led them to view out-of-home placement as their only option.

Demographic profiles for placement tendency groups

Research question: Are there demographic differences between placement tendency groups?

Child characteristics

Data on the sex, age, disability and schooling of the children with disabilities and high support needs across the three placement tendency groups are presented in Table 15. *Considered placement* and *Taken action* groups were aggregated for this and all other between group comparisons on I1 data due to the small numbers in each group. Note however that the raw data is included in the tables to assist understanding of the demographic profile of the entire sample of primary parent-carers. No statistically significant association was found between placement tendency and sex or age of the child.

A significant association was found between placement tendency group and primary diagnosis at both I1 ($\chi2=6.4$, $p<.05$) and I2 ($\chi2=14.2$, $p<.01$). Families with children with physical disabilities were significantly less likely to be in the *Considered placement* or *Taken action* groups. A significant association was also found between placement

tendency group and the child's school placement at both I1 ($\chi 2$=9.6, p<.01) and I2 ($\chi 2$=13.6, p<.01). Families with children attending special schools were significantly more likely to be in the *Considered placement* or *Taken action* groups.

To further explore the relationship between placement tendency, primary diagnosis and schooling, these variables were dummy coded and entered into a multiple regression analysis along with Global Child Hassle. These variables together explained a significant 24% (R^2=.24) of the variance in placement tendency at I1 (F=4.8, p<.005) and a significant 38% (R^2=.38) at I2 (F=8.8, p<.001). However, with all items entered together in a single step, only Global Child Hassle emerged as a significant predictor, with a significant T-value at I1 and I2. These findings suggest that it is not disability type or schooling *per se,* but rather the demands placed on the family by the child's medical/health care needs and behaviours that influence placement tendency. Disability type and school placement act as proxy indicators for these demands.

Table 15: Placement tendency demographic profiles – Child characteristics

	Never considered		Considered placement		Taken action	
	I1 (n=55)	I2 (n=45)	I1 (n=21)	I2 (n=19)	I1 (n=5)	I2 (n=14)
Sex (m/f)	32/23	24/21	14/7	13/6	4/1	10/4
Age (years)	9.15		9.86		10.00	
Disability						
Physical	29 (52.7%)	28 (62.2%)	6 (28.6%)	4 (21.1%)	0 (0%)	3 (21.4%)
Intellectual	19 (34.5%)	12 (26.7%)	12 (57.1%)	12 (63.2%)	2 (40%)	7 (50%)
Autism	7 (12.7%)	5 (11.1%)	3 (14.3%)	3 (15.8%)	3 (60%)	4 (28.6%)
Schooling						
Fully integrated	13 (23.6%)	12 (26.7%)	1 (4.8%)	2 (10.5%)	0 (0%)	0 (0%)
Special class	21 (38.2%)	18 (40%)	5 (23.8%)	6 (31.6%)	1 (20%)	2 (14.3%)
Special School	21 (38.2%)	15 (33.3%)	15 (71.4%)	11 (57.9%)	4 (80%)	12 (85.7%)

Primary parent-carer characteristics

Table 16 presents data on the sex, age, marital and employment status of the primary parent-carers in the three placement tendency groups. No association was found between placement tendency and these primary parent-carer characteristics.

Table 16: Placement tendency demographic profiles – Primary parent-carer

	Never considered		Considered placement		Taken action	
	I1 (n=55)	I2 (n=45)	I1 (n=21)	I2 (n=19)	I1 (n=5)	I2 (n=14)
Sex (m/f)	4/51	4/41	0/21	0/19	0/5	0/14
Age (years)	41.7	41.6	42.1	41.5	45.4	43.7
Marital status						
sole parent	8 (14.5%)	5 (11.1%)	2 (9.5%)	1 (5.3%)	3 (60%)	6 (42.9%)
two parent	47 (85.5%)	40 (88.9%)	19 (90.5%)	18 (94.7%)	2 (40%)	8 (57.1%)
Employment status						
unemployed	17 (30.9%)	14 (31.1%)	8 (38.1%)	9 (47.4%)	2 (40%)	4 (28.6%)
part-time/casual	27 (49.1%)	19 (42.2%)	9 (42.9%)	10 (52.6%)	2 (40%)	6 (42.9%)
full-time	11 (20%)	12 (26.7%)	4 (19%)	0 (0%)	1 (20%)	4 (28.6%)

Family characteristics

Table 17 presents data on the household composition, housing and income of families across the three placement tendency groups. No association was found between placement tendency, income group, number of children and having more than one child with special needs. A significant association was found between placement tendency and the number of adults in the home. On average, families in the *Never Considered* placement group had more adults in the home at I1 (t=2.7, p<.01) and I2 (F=3.3, p<.05). Significant between group differences were also found for housing, with those families who were either renting or share-housing least likely to be in the *Considered placement* group at I1 ($\chi2$=8.5, p<.05). No such association was found at I2.

Table 17: Placement tendency demographic profiles – family characteristics

	Never considered		Considered placement		Taken action	
	I1 (n=55)	I2 (n=45)	I1 (n=21)	I2 (n=19)	I1 (n=5)	I2 (n=14)
Housing						
Rent/share	17 (30.9%)	12 (26.7%)	2 (9.5%)	3 (15.8%)	0 (0%)	2 (14.3%)
Home/mortgage	22 (40%)	20 (44.4%)	14 (66.7%)	12 (63.2%)	5 (100%)	9 (64.3%)
Own home outright	16 (29.1%)	13 (28.9%)	5 (23.8%)	4 (21.1%)	0 (0%)	3 (21.4%)
Income *per annum*						
<$30,001	7 (15.2%)	6 (16.7%)	1 (5%)	1 (5.3%)	3 (75%)	4 (33.3%)
$30,001-$60,000	15 (32.6%)	9 (25%)	8 (40%)	8 (42.1%)	0 (0%)	3 (25%)
>$60,000	24 (52.2%)	21 (58.3%)	11 (55%)	10 (52.6%)	1 (25%)	5 (41.7%)
Household composition						
Mean no. Adults	2.13	2.09	1.90	2.16	1.60	1.79
Mean no. Children	2.47	2.47	2.95	3.11	2.20	2.43
> 1 child - special needs	10 (18.2%)	6 (13.3%)	2 (9.5%)	2 (10.5%)	1 (20%)	4 (28.6%)

Support and service utilization

Table 18 presents data for each placement tendency group at I1 and I2 on use of respite and after school care, specialist services, availability of alternative caregivers and the help the primary parent-carer receives with child care and domestic workload. A significant difference was found between placement tendency and use of respite care services. Families using respite care at least fortnightly were those most likely to be in either the *Considered placement* or *Taken action* groups at I1 (F=4.7, p<.05) and I2 (F=14.1, p<.001).

Table 18. Placement tendency demographic profiles – support & services

	Never considered		Considered placement		Taken action	
	I1 (n=55)	**I2 (n=45)**	**I1 (n=21)**	**I2 (n=19)**	**I1 (n=5)**	**I2 (n=14)**
Uses respite care						
Never	26 (47.3%)	23 (51.1%)	6 (28.6%)	8 (42.1%)	1 (20%)	1 (7.1%)
At most monthly	17 (30.9%)	15 (33.3%)	8 (38.1%)	7 (36.8%)	0 (0%)	2 (14.3%)
At least fortnightly	12 (21.8%)	7 (15.6%)	7 (33.3%)	4 (21.1%)	4 (80%)	11 (78.6%)
Uses after school care	10 (18.2%)	9 (20%)	1 (4.8%)	1 (5.3%)	2 (40%)	3 (16.7%)
Services for child[a]						
In school	1.85	1.79	2.48	2.16	1.80	2.29
out-of-school	1.27	1.38	0.57	0.58	1.00	0.64
No of available carers[b]	1.58	1.56	1.94	2.05	1.60	2.07
Child care load—help[c]						
Within household	3.78	4.11	3.67	3.79	1.80	2.77
Outside assistance	3.09	3.00	3.86	3.21	3.00	4.14
Domestic load—help[c]						
Within household	3.05	3.02	2.76	2.42	1.20	1.93
Outside assistance	0.95	0.76	1.24	1.68	1.60	1.71

[a] Specialist services such as occupational therapy, physiotherapy and speech pathology

[b] Mean number of people available to care for the child in the primary parent-carer's absence, including paid carer/s, the child's siblings, adult friends or relatives etc.

[c] Mean level of help the primary parent-carer receives, rated by interviewer on a scale of 0-8, where 0 means no assistance.

In sum, demographic features of families who had C*onsidered placement* or *Taken action* toward placement of their child with a disability included *fewer adults in the household*, *a child with intellectual disability or autism*, *special school attendance,* and *use of respite care.* These variables together explained a significant 31% of the variance in placement tendency at I1 (F=8.1, p<.001), and 38% of the variance at I2 (F=10.3, p<.001), computed using regression analysis with all variables entered in a single step. Examination of T-values showed that autism, use of respite care and number of adults in the household contributed significantly to the prediction of placement tendency at I1 and I2, with special school attendance also contributing at I2.

Coping style, health status and placement tendency

Research questions: Is placement tendency related to primary parent-carer coping style?
Is placement tendency related to primary parent-carer health?

A significant correlation was found between placement tendency and *Non-productive Coping* at I2 (r=.34, p<.01). In other words, a tendency toward placement was associated with more frequent use of *Non-productive Coping* strategies such as worrying, self-blame, 'blocking out', and getting sick. No significant correlation was found between placement tendency and use of any of the other three coping styles.

No significant correlations were found between placement tendency and primary parent-carer health status, with one exception. Placement tendency and primary parent-carer 'Vitality' were significantly (p<.05) correlated at I1 (r=-.27). Placement tendency and Vitality were not significantly correlated at I2.

Placement tendency and family well-being

Research question: Is placement tendency related to family well-being?

Placement tendency and family well-being were found to be highly correlated at I1 (r=-.423, p<.001) and I2 (r=-.481, p<.001). Those families who had *Never Considered* placement had, on average, greater family well-being than families who had *Considered placement* or *Taken action* at I1 (t=2.8, p<.01) and I2 (F=11.9, p<.001). Table 19 presents cross-tabulated data for well-being and placement tendency groups. Figures 9 and 10 show group differences graphically. All five families who had *Taken action* at I1 were *Struggling* families. At I2, almost half of the *Struggling f*amilies had *Taken action*, and 11 of 14 families who had *Taken action* were *Struggling* families. Analysis of the cross-tabulated data at I2 demonstrated a highly significant statistical association (χ2=27.6, p<.001).

Table 19: Cross-tabulation of family well-being and placement tendency groups

	Struggling		Doing OK		Thriving	
	I1 (n=17)	I2 (n=23)	I1 (n=44)	I2 (n=34)	I1 (n=20)	I2 (n=21)
Never considered placement	7 (41.2%)	4 (17%)	33 (75%)	25 (73%)	15 (75%)	16 (76%)
Considered placement	5 (29.4%)	8 (35%)	11 (25%)	6 (18%)	5 (25%)	5 (24%)
Taken action toward placement	5 (29.4%)	11 (48%)	0	3 (9%)	0	0

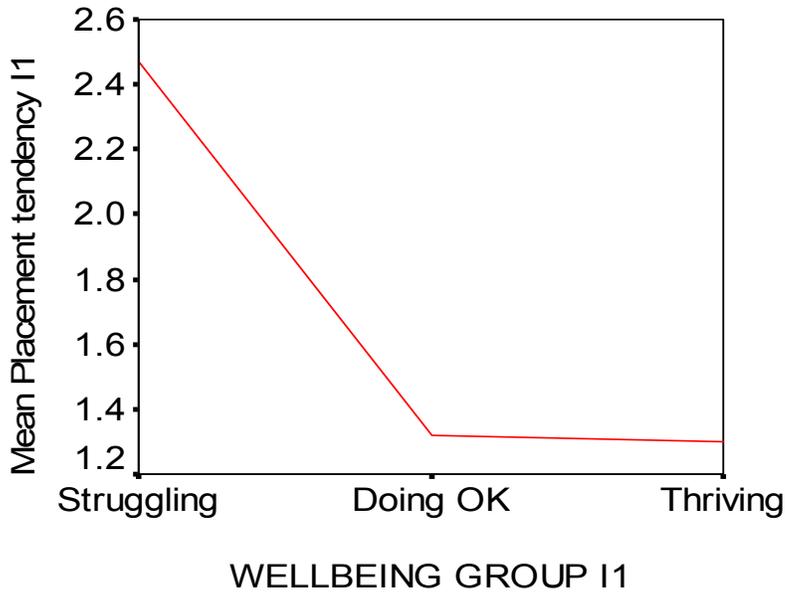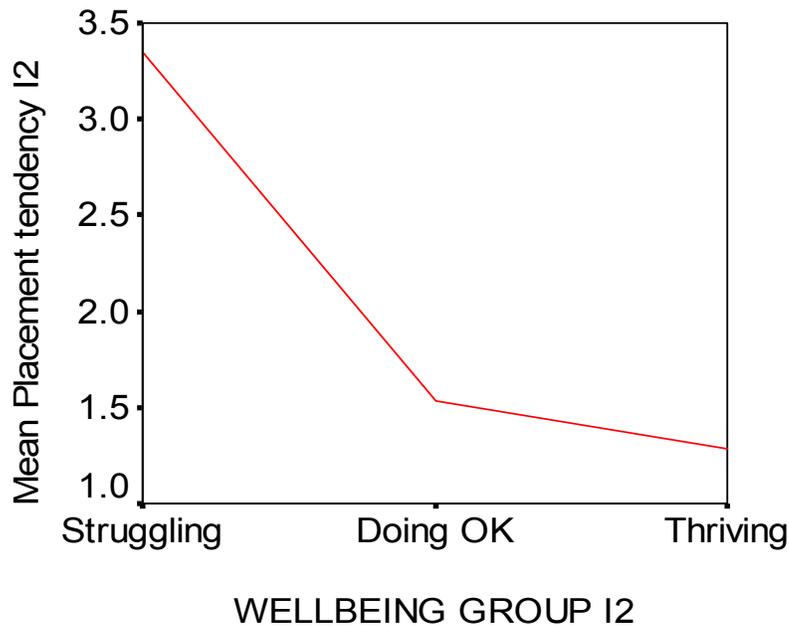**Figure 9: Placement tendency and family well-being at I1**

Figure 10: Placement tendency and family well-being at I2

WELLBEING GROUP I2

Placement tendency and ecocultural variables

Research question: Which ecocultural variables best predict placement tendency?

Multiple regression analysis was employed to determine the extent to which items in each of the seven ecocultural dimensions together predicted placement tendency and to identify which items had significant T-values. Table 20 lists the items in each dimension with significant T-values, and the proportion of variance (R^2 value) in placement tendency explained by each dimension.

Two of the seven ecocultural dimensions at I1, and four of the seven dimensions at I2 demonstrated a significant association with placement tendency. The significant dimensions were:

- Balancing Needs and Demands (I1, F=2.9, p<.005) (I2, F=2.6, p<.01)

- Integrating the Child (I2, F=4.8, p<.001)

- Accessing Special Services (I2, F=3.2, p<.01)

- Home and Neighbourhood (I1, F=3.5, p<.05) (I2, F=8.9, P<.001)

The dimension of *Balancing Needs and Demands* was the strongest consistent predictor of out-of-home placement tendency. Notably no significant association was found between placement tendency and the dimensions of *Sharing Workload and Responsibility*, *Financial Resources* or *Spiritual Beliefs and Affiliation*.

Table 20: Salient eco-cultural predictors of placement tendency

Dimension	Items with sig. T-values	I1 R^2 value	I2 R^2 value
Sharing Workload and Responsibility	Ns#		
Balancing Needs and Demands	*Child is viewed as an opportunity or positive development rather than a burden or bad luck (I1)* *Family arranges time and schedules around the child (I1)* *Time availability of primary parent-carer for the child (I1, I2)*	.37	.41
Integrating the Child	*Family goal for the child to be integrated into the typical, everyday world (I2)*	.24	.41
Accessing Special Services	*Information recently received from professionals regarding the child's diagnosis and functioning (I2)*	.12	.27
Financial Resources	Ns#		
Home and Neighbourhood	*Use of neighbourhood places and services (I1, I2)*	.08	.19
Spiritual Beliefs and Affiliation	Ns#		

Ns# = not significant

The next step involved multiple regression with all significant items (i.e. those with significant T-values) entered in a single step.   These items together explained a significant 28% of the variance in placement tendency at I1 (F=4.8, p<.001), and a significant 45% of the variance at I2 (F=9.6, p<.001). However, only two items made a significant contribution to the prediction of placement tendency. These were:

◆   Family goal for the child to be integrated into the typical, everyday world (I1, I2)

◆   Child is viewed as an opportunity or positive development rather than a burden or bad luck (I2)

The findings indicate that the contributions made by the other ecocultural predictors of placement tendency as listed in Table 20 are subsumed by these two key variables. Figures 11 and 12 show the near monotonic relationship between these two key variables and placement tendency groups at I1 and I2 respectively.

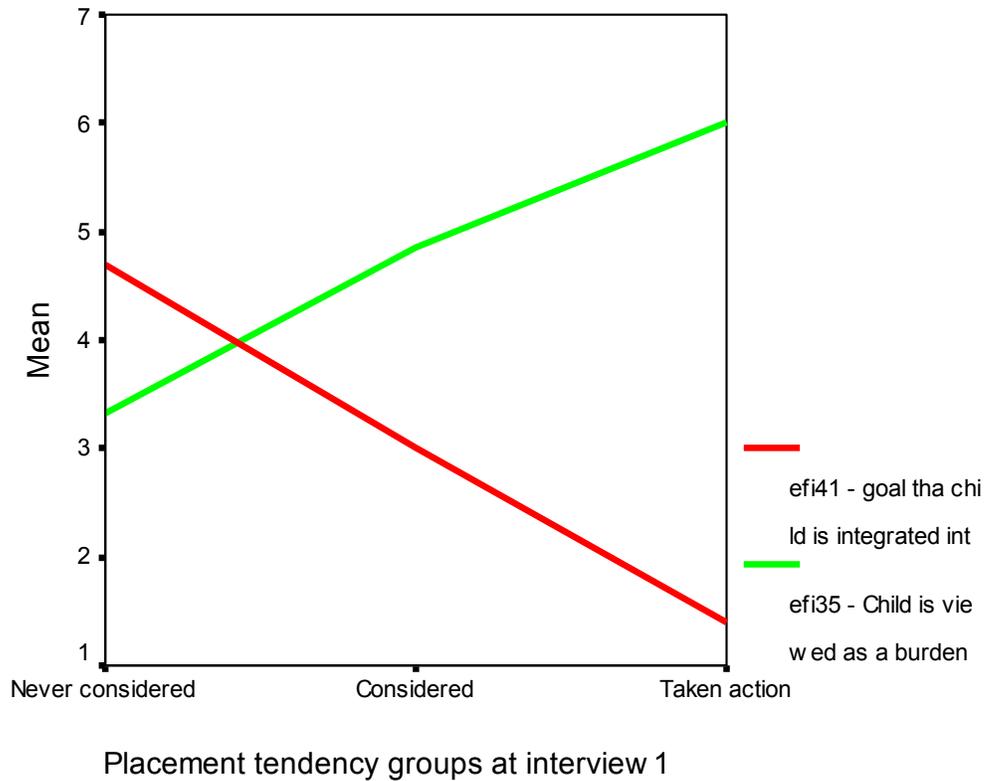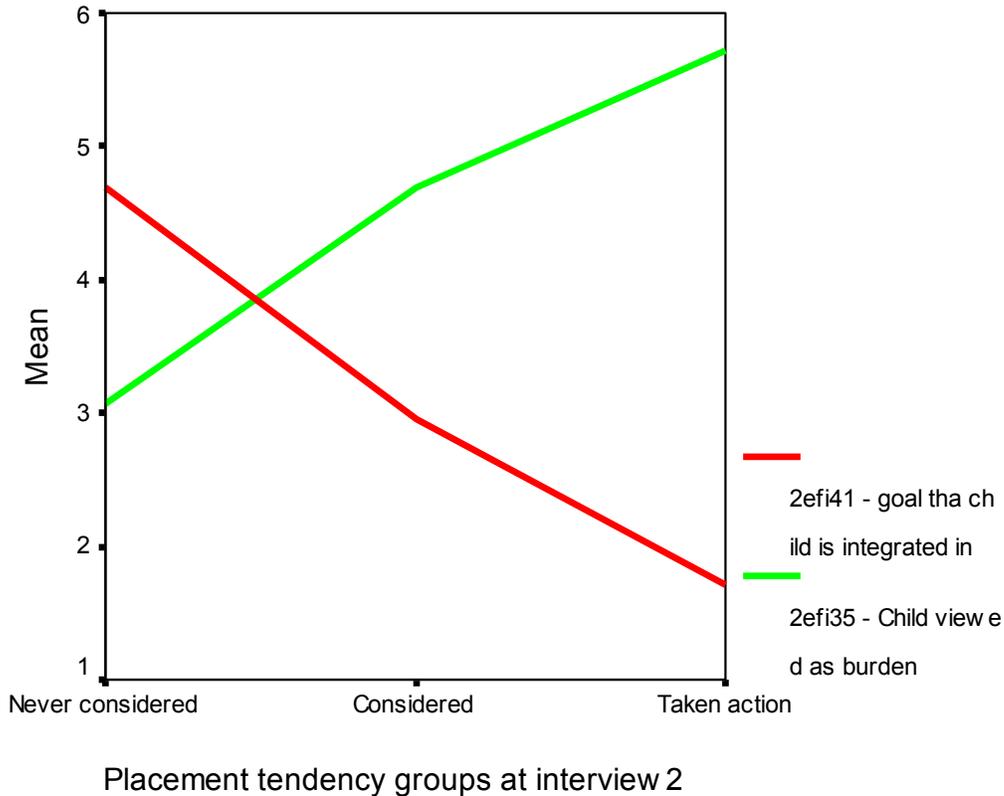**Figure 11: Placement tendency and key ecocultural predictors at I1**

Placement tendency groups at interview 1

Figure 12: Placement tendency and key ecocultural predictors at I2

Placement tendency and child health and hassle

Research question: Is placement tendency related to demands placed on the family by the child's health and/ or behaviours?

A strong relationship was found between placement tendency and the demands placed on the family by the child's behaviours. There was a significant correlation between placement tendency scores and six out of seven dimensions of the Child Health and Hassle Scale at I1 and I2. No significant correlation was found between placement tendency and child's medical/health care needs.   On all other subscales, the Pearson correlation coefficients ranged from r=.30 (Aberrant Behaviours) to r=.45 (Global Child Hassle) at I1, to r=.34 (Communication) to r=.58 (Global Child Hassle) at I2.

T-tests were computed to examine differences between *Never Considered* and *Considered placement* and *Taken action* groups (combined) at I1 on each Child Health and Hassle subscale. Figure 13 shows the differences between the three placement

tendency groups on each Child Health and Hassle subscale at I1. Significant between group differences were found on five subscales: Communication ($t=-2.2$, $p<.05$), Interaction ($t=-2.8$, $p<.01$), Responsiveness ($t=-3.4$, $p<.005$), Appropriacy ($t=-5.2$, $p<.001$), and Global Child Hassle ($t=-4.0$, $p<.001$).

Figures 14 shows the differences between the three placement tendency groups on each Child Health and Hassle subscale at I2. One-way ANOVA revealed significant ($p<.05$) between group differences on all subscales with the exception of the child's medical/health care needs. Bonferroni contrasts revealed that all three groups were significantly different from each other on Interaction ($F=15.4$, $p<.001$) and Global Child Hassle ($F=20.9$, $p<.001$) subscales. Those families who had *Taken action* toward placement reported significantly higher demands generated by Responsiveness ($F=13.5$, $p<.001$) and those families who had *Never Considered* placement reported significantly less demands generated by Appropriacy ($F=21.9$, $p<.001$), compared to both other groups. Finally, there were two subscales where only *Never Considered* and *Taken action* groups differed significantly. These were Aberrant Behaviours ($F=8.5$, $p<.001$) and Communication ($F=5.1$, $p<.01$).

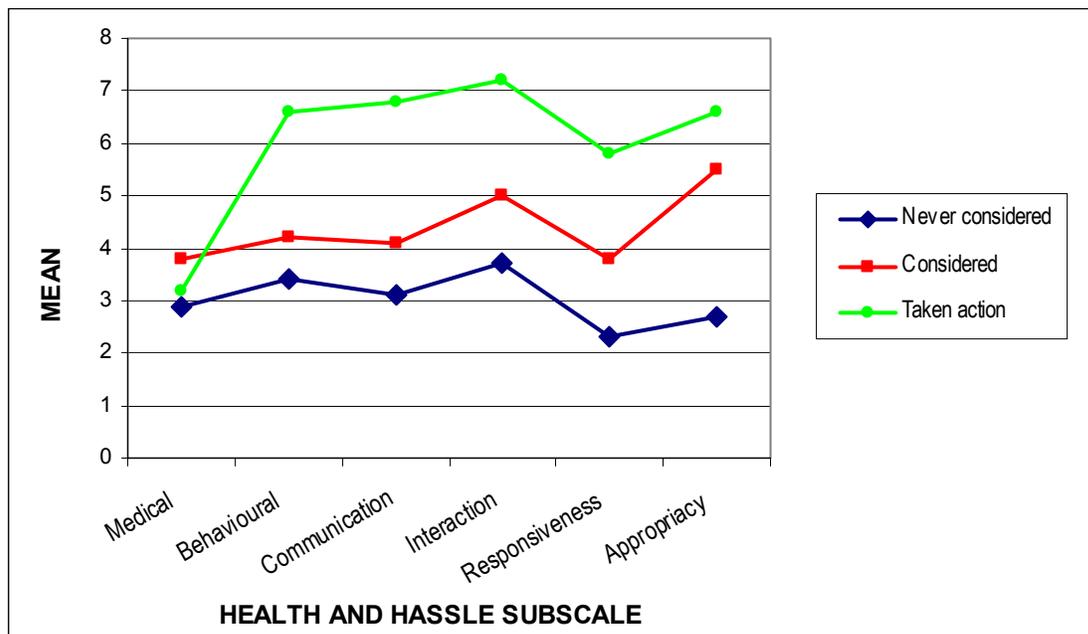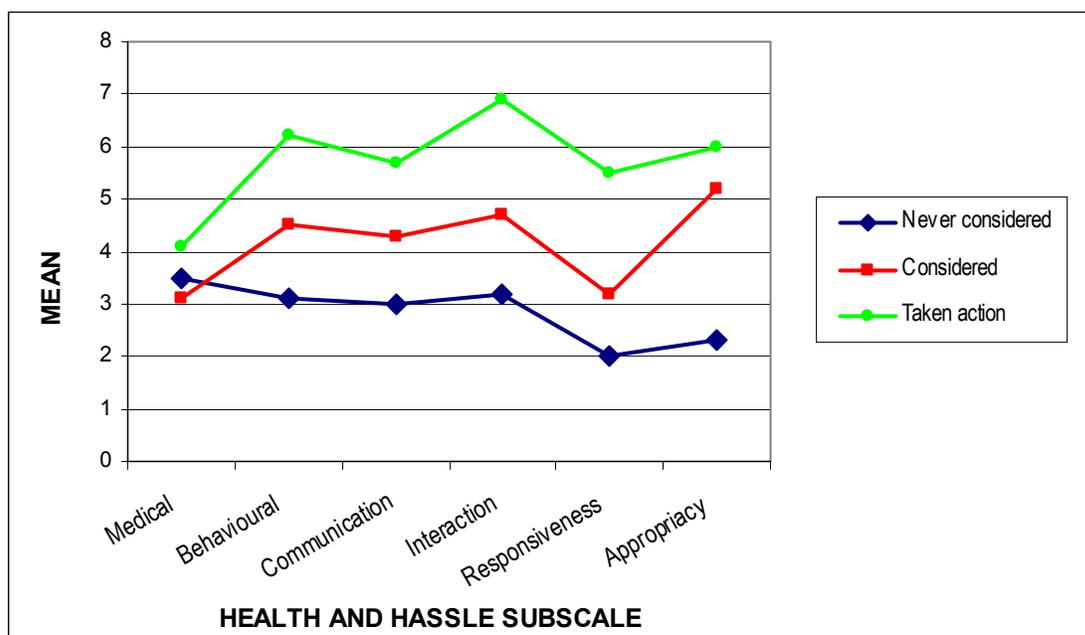**Figure 13: Placement tendency groups and Child Health & Hassle at I1**

Figure 14: Placement tendency groups and Child Health & Hassle at I2

Themes from the qualitative data on placement tendency

Several themes emerged from the qualitative data that assist in understanding how families of school-age children with disabilities and high support needs think about continuing to care for their child at home or out-of-home placement.

Children spending a significant proportion of time at school

The children in this study were all of school age and therefore spent a considerable part of their day and the entire year at school. In one sense this could be thought of as 'out of home'. This time spent away from home potentially eased some of the pressures on families.

Getting your name on the placement list

Families were acutely aware of the shortage of quality placements and, encouraged by professionals, many had put their names on a waiting list even if they currently had no desire to place their child. This action could be thought of as insurance for a possible future when they no longer desired or were unable to provide full-time care for their child. Trying to find an appropriate place for their child was a source of considerable consternation, particularly as many felt that they must start looking at placement options before they were ready. Families who desired placement talked about being keen to have a supportive caseworker to assist them investigate varied and flexible placement options.

The older the child the more thought given to the future

Families with older children toward the thirteen-year age limit were more likely to discuss their family's future after their child's schooling had finished. Talking about the future usually included thinking about where their older adolescent might live and this included out-of-home placement for some families. Once children become young adults, living away from home is an expected normal transition. However this is not typically the case with young adults with disabilities and high support needs. Rather they are more likely to be thought of as being dependent, needing a degree of 'protection', and therefore needing to live in supported accommodation.

Issues that delayed turning serious consideration of placement into action

Three issues were frequently mentioned as delaying placement for those families who were seriously considering this option. The first was the fact that their children were still relatively young. The second was the extreme shortage and prohibitive expense of desirable placement options and long waiting lists. Finally, they mentioned the continuing presence of formal support (such as increased respite hours) and informal support (such as support from a spouse or other family members) that eased their care load and allowed them to keep caring for their child at home.

Staying involved in their child's life

The primary criterion used by those families seriously considering placement options was how easily they could remain involved in their child's life. Families were looking for somewhere for their child to live close to their family home and with flexible opportunities so they could remain involved. Residential schools for children with disabilities were repeatedly mentioned as a much desired but rarely available and often prohibitively expensive placement alternative. These were seen as "being like boarding school" and so considered to be a more socially and psychologically desirable alternative to the "disability institution" that seemed to be their only other choice. Residential schools also offered the opportunity to have their children home at weekends and for holidays. Primary parent-carers' views on this are supported by findings from the studies of Blacher and her colleagues (e.g., Blacher, 1992; Blacher, 1994; Baker, 1996) who found that close geographical proximity, being welcoming and willing to share decision-making with family members are all factors which promote continuing involvement by the family post-placement of their child.

Not if, but when

It appeared that once families began to seriously consider placement they were on the "placement treadmill" that moved towards placement at a speed over which they had little or no control. This movement is also supported by work by Hannerman & Blacher (1998) who found that once families begin to think about placement it becomes a matter of when, rather than if, they will place their child out of home. Ironically, the system 'supporting' families to care for their child at home also provided the impetus for families to take action about placement. Aware of the lack of quality placement options available, coming to realize that their child could not live at home indefinitely, and prompted by advice from professionals, families put their name on the "departmental database" to ensure a place.

As one mother reported, "the thing we have done is, well someone recommended to us last year that we put our name down on the list that DoCS has to hand over every three months where it says that the parents are interested in permanent placement. It was suggested to us that you haven't got a hope in hell of getting it (placement), but when the time comes, you can say 'well our name has been on the list since such and such an age.' So it is a bit more so your case is down on file, but really has little relevance for the moment".

Another commented, "I mean I would like out-of-home placement to be later on, but I know if something came up now, well by not taking it, then something might not come up for another ten years. So that uncertainty is pre-empting me, making me act almost before I am ready because I know the system is unstable". As with other families seriously considering placement, this mother could envisage a time in the future when placement might be necessary and perhaps required urgently because of poor parent-carer health. Knowing this and the state of the system moved families to begin the placement process as this mother reports, "…I mean I thought God what if something happened to us, like if my back went or anything else happened that meant I couldn't look after her… its not like I can ring up and say 'I need something.' So I actually said to the caseworker 'I don't want her placed yet, I just want her placed in the system so maybe when she is 15, 16, 17 or 18 or it has to happen, it can.*"

Change in out-of-home placement tendency during the study period

Research question: Which aspects of everyday family life are associated with change in placement tendency?

As noted above, the number of families who had made enquiries, taken steps to place or who had made all the arrangements more than doubled between I1 (n=5, 6.2%) and I2 (n=14, 17.9%).   The number of families who actually changed placement tendency groups is represented graphically in Figure 15.

Figure 15:   Changes in placement tendency group between I1 and I2

Never Considered	Considered	Taken action	Total
4 (7.7%) ⟶	5 (23.8%) ⟶		9
4 (7.7%) ⟶			4

Hierarchical regression analysis was employed to determine whether family well-being at I1 contributed significantly to the prediction of placement tendency at I2 (12-15 months later), after controlling for placement tendency at I1. Placement tendency at I1 explained a significant 60% of the variance in placement tendency at I2 (F=114.6, p<.001). Family well-being at I1 did not improve the prediction significantly.

The next step in the analysis focused on the two key ecocultural variables associated with placement tendency, namely, *Family goal for the child to be integrated into the typical, everyday world,* and, *Child is viewed as an opportunity or positive development rather than a burden or bad luck*. Employing hierarchical regression analysis and controlling for placement tendency at I1, these key ecocultural variables together made a significant contribution to the prediction of placement tendency at I2 (F change = 5.4, p<.01). However, only one of the items, that is, Family goal for the child to be integrated into the typical, everyday world, had a significant T-value.

Finally, hierarchical regression analysis was used to examine the potential contribution of Global Child Hassle to the prediction of future placement tendency, again controlling for placement tendency at I1. The findings showed that Global Child Hassle did contribute significantly to the prediction of placement tendency at I2 (F change =8.6, p<.005).

Overall the findings suggest that families who:

- have already considered, made enquiries or taken some other action toward placement, and

- are struggling to sustain their everyday routines in the face of their child's health care needs and or disruptive behaviours (i.e. global child hassle), and

- who do not see the integration of their child into the typical, everyday world as a realistic (or perhaps desirable) goal,

are more likely to move towards placing their child out of home in the near to medium term future.

FINDINGS AT A GLANCE

- Approximately 60% of families at the first interview had never considered placing their child out of home. A small proportion (6%) had already taken action to do so. This group had increased to nearly 18% by the time of the second interview around one year later.

- Higher demands (as perceived by the primary parent-carer) placed on the family by the child's medical/ health care needs and behaviours influence placement tendency. Families who were considering placement or who had taken action included fewer adults in the household (particularly lone mothers), a child with intellectual disability or autism, and special school attendance.

- Families for whom social integration of the child is an important goal and those who view their child as an opportunity rather than a burden are the least likely to be seriously considering placement. Conversely, families are more likely to give serious consideration to placement or take action if there are fewer adults in the household, the child with special needs has intellectual disability or autism and attends a special school, and they frequently use respite care.

- Family well-being is related to placement tendency in that the majority of families who had taken action about placing their child (11 out of 14 at I2) were Struggling families

- Families moving closer to placing their child out of home are those who have already gone some way to considering this option and are having difficulty sustaining their daily routines in the face of their child's needs and demands and at the same time are not so concerned that their child be integrated into the normal, everyday world.

- Service system barriers such as lack of appropriate and quality placements not only challenge families to find suitable alternative care for their child but also set in train a process to ensure a place irrespective of the timeliness or readiness of the family to consider out-of-home placement as an option for their child.

7

Conclusion

Contents

Introduction

In this final section we summarise the findings of this research and development project and present some suggestions for future research to address the concerns about the continuing requests from families of disabled children for out-of-home placement in the face of policy and service practices designed to alleviate - or at least substantially reduce - the need for such requests. The suggestions we present are grounded in the findings of the study and other research findings.

The central tenet of this concluding section is that there needs to be a substantive change in the way that caring at home or out-of-home care for disabled children is conceptualised. We argue that while caring at home continues to be thought about as 'triumph over adversity', service providers are positioned to frame their offerings to the family in terms of temporary relief from the ongoing burden of care until permanent relief from this burden becomes available or is forced upon the family by unforseen circumstances. In other words, concerns about whether families can maintain out-of-home care become enmeshed in social and policy debates about community care (and frequently about the amount of respite available) rather than in whether families can sustain meaningful routines congruent with their family goals and wishes and the likely prospect of their being able to do so into the future.

SUMMARY

The broad purpose of the study was to investigate family well-being and out-of-home placement tendency among families with children with disabilities aged 6-13 and high support needs. In doing so, we aimed to better understand differences in family well-being and the factors influencing this in contrast to the greater proportion of the literature, which focuses on the negative impact of disability on family life.

Eighty-one families from the Northern Metropolitan and Eastern Sydney regions took part in semi-structured interviews over a two-year period through 1999-2000. The interview used tools developed by the Ecocultural Scale Project and adapted for the purposes of this project. The interview format is semi-structured and conversational in style permitting a narrative open-ended interviewing approach across ten domains of family life and an opportunity for the primary parent-carer (most frequently the mother) to "tell their story". Interview participants also completed several standard measures on health, coping, child health and hassle, and out-of-home placement tendency.

KEY FINDINGS

The families

◆ Most families in this study were two parent families with higher educational qualifications than the general population and a better employment rate than other carers in NSW. Although few families had low incomes, around 30% of the families reported insufficient income to meet their needs. One in two of the children attended special schools, a figure six times higher than the NSW percentage and one that suggests these children have high to very high support needs. The families were frequent users of respite services with over half (59%) of the children attending some form of respite at least monthly, and over a quarter (28%) attending at least fortnightly. Overall, children attending special schools and children who attended respite care at least fortnightly were perceived to be more demanding or unsettling to established everyday routines.

◆ The primary parent-carers in the families in this study suffered considerably poorer health in comparison with the Australian population norms. Most primary parent-carers used *Sharing* as a productive coping style. This involved them in dealing with the problem and turning to others for support. However, roughly one in two primary parent-carers reported using *Non-productive Coping* strategies at least sometimes, which is of concern given the strong association between this coping style and poor mental health status.

Family well-being

◆ Around half of the families were doing okay with regards to their family well-being (that is, up to one standard deviation either side of the mean). Of the other half, just over a quarter of the families belonged to the Thriving group (that is, one standard deviation or more above the mean on family well-being) with the remaining just under a quarter of families placed one standard deviation or more below the mean with regard to their family well-being (Struggling group).

◆ Although family well-being appears a reasonably stable construct (64% of families remained in the same family well-being group at the time of the second interview) just over one third of families experienced change in family well-being to the extent that they changed family well-being groups. Change in family well-being is associated with events or circumstances that act to unsettle established family routines. This may be a single event or a cluster or chain like sequence of events. Change in family well-being can be for the better or the worse.

◆ Around 19% of families experienced a downturn in their family well-being during the course of the study. For these families, increased care demands associated with their disabled child and increased uncertainty about the present and the future for their disabled child and their family had made it difficulty to establish or sustain a meaningful and congruent everyday family routine. On the other hand, around 14% experienced an up-turn in their family well-being by the time of the second interview. For these families a positive change in their workforce participation or their financial resources, their increasing satisfaction with their child's school placement or overall progress, and/or extra help coming into the family or more time out from caregiving all contributed to their enhanced family well-being.

◆ Thriving families present different demographic characteristics to Struggling families. Thriving families are typically two parent households, higher family incomes and full integration of their child with a disability into a mainstream school. These three variables alone explain a significant 25% of the variance in family well-being at I1 (F=8.6, p<.001) and 28% of the variance at I2 (F=9.6, p<.001), computed using regression analysis with all variables entered in a single step. These demographic features could be described as an *advantage* profile of family well-being.

◆ Families in the Struggling group exhibit the following demographic characteristics: sole parent households, relatively low family incomes, more than one child with special needs, special schooling and relatively frequent use of respite care. These five variables alone explain a significant 36% of the variance in family well-being at I1 (F6.6, p<.001), and 31% of the variance at I2 (F=5.2, p<.001), computed using regression analysis with all variables entered in a single step. These demographic features could be described as a *risk profile* of family well-being.

◆ Primary parent-carers in the Struggling group fared significantly worse than primary parent-carers in both other groups in terms of their physical and mental health. They also perceived more demands in terms of their child's medical/ health care needs and behaviours than did those in the Thriving group.

Out-of-home placement tendency

◆ Most of the families (93%) at the time of first interview had not seriously considered placing their child out of home. A small proportion (6%) however had already taken action to do so. By the time of the second interview this small group of families had trebled to almost 18% of all families. The families most likely to take action were those with fewer adults (particularly lone mothers), a child with intellectual disability or autism, and a child attending special school. These families were also more likely

to perceive much greater demands placed on the family by their child's medical/ health care needs and behaviours.

◆ Not surprisingly, family well-being is highly correlated with placement tendency. Those families who have greater family well-being are much less likely to ever consider placing their child out of home. On the other hand, struggling families are more likely to seriously consider placing their child out-of-home. Eleven out of the fourteen families who had taken action by the time of the second interview were in the Struggling group. The *Balancing Needs and Demands* dimension was the strongest predictor of out-of-home placement tendency. The relevant items include family goal for the child to be integrated into the typical, everyday world and the child being viewed as an opportunity or positive development rather than a burden or bad luck.

◆ Families moving closer to placing their child out of home are those who have already gone some way to considering this alternative. This finding confirms those of Blacher and her colleagues who have demonstrated that once a family begins considering placement for their disabled child it is not a matter of will this occur but rather when (e.g., Blacher, 1990; Blacher & Hannerman, 1998). A striking finding in this study is the 'culture' of professional advice recommending that families add their names to waiting lists for out-of-home care. This may be influencing families to consider out-of-home placement and to take action to ensure a 'place' before no longer caring for their child at home is a desired alternative.

Future directions

Family well-being

Drawing on these key findings and the findings of colleagues (e.g., Gallimore et al., 1993; Gallimore et al., 1999; Grant & Whittell, 2000; Knox et al., 2000) we propose that the 'assessment' of families of children with disabilities needs to recognize the ongoing project in which families engage – that is, the construction and maintenance of a congruent, meaningful and sustainable family routine. This ongoing project is central to family life. Families who are unable to create this routine or experience disruptions for the worst in their routine, experience poor family well-being and are much more likely to take action to place their child out-of-home. In contrast, those families who are able to create and sustain a workable routine experience more positive family well-being and are much less likely to seek out-of-home placement for their disabled child.

Strikingly, family well-being is determined by the ecocultural niche in which the family is located – this niche comes from, and is determined by the family's proactive and reactive efforts in working to maintain their everyday family life. Noting the critical importance of this ongoing family project, assessment of families of children with disabilities needs to recognize that families are multi-faceted and multi-layered organisms in which family members live and interact together. Family responses are not only focused on, or determined solely by the needs of the disabled child. Rather the central process is the establishment and maintenance of workable daily routines. Success or the lack of in doing so is reflected in family well-being. The strongest predictor of family well-being at both interview times was the ecocultural dimension of *Balancing Needs and Demands*. Seven key ecocultural variables predict 86% and 84% of the variance in family well-being at the first and second interview times respectively.

To recap, *Struggling* families are those having most difficulty balancing needs and demands. Many of these families (but not all) are sole parent households, have relatively low family incomes, with more than one child with special needs usually placed in a special school, and these families use respite care more frequently. While families with these socio-economic characteristics are also more likely to have taken action to place their child out of home not all families in the Struggling and Taken Action groups share these socio-economic characteristics and structural disadvantage. While certain socio-economic and demographic characteristics are associated with family well-being (as noted above under *Family Well-being*), these characteristics are not the sole determinants of family well-being outcomes. The active role of the family and their perception of their circumstances in line with their values, beliefs and goals cannot be spelt out too strongly.

Taking these seven key variables and their constituent ecocultural items into account the first three authors Gwynnyth Llewellyn, David McConnell and Kirsty Thompson (University of Sydney) have developed a draft protocol designed to assist practitioners working with families with children with disabilities. This protocol focuses on exploring daily routines using the predictor ecocultural items as a framework for a narrative, semi-structured interview. Our hypothesis is that using a family well-being protocol will enable practitioners to more clearly identify the ways in which families construct their daily routine, what is working for the family and what is not, and what factors support or challenge the establishment and sustainability of a meaningful routine which is congruent with and meets the needs of all family members. In line with the theoretical assumptions underpinning this work, understanding the family's ecocultural niche through their daily routines is essential prior to practitioners considering the configuration of services and support that will ensure a 'best fit' for each particular family. Ensuring 'goodness of fit' between everyday family life and service support is critical for all families however there is an assumed hierarchy of need beginning with those families who are struggling. These

families are most in need of responsive support and services well-crafted to assist them to develop a more sustainable, meaningful and congruent everyday life. Further, we hypothesize that identifying ahead of time those events, sequences, or transition points likely to interrupt everyday routines will provide practitioners with a useful tool to prioritise their services taking into account not only the current family situation but also potential 'danger' periods which can then be addressed ahead of full-blown crisis situations.

In sum, we argue that understanding family well-being is fundamental to understanding why some families do well while others in apparently similar circumstances do not. Further we argue that finding out about family well-being will assist practitioners to understand how well (or otherwise) particular families are doing. Equipped with this knowledge, practitioners are then in a better position to assist struggling families to improve their well-being. Family well-being indicates the extent to which the family's daily routine is meaningful and appropriate to their goals and values, congruent with the needs of all family members, and sustainable even in the face of obstacles and changing circumstances. We believe there is an urgent need to further develop and subsequently conduct a controlled trial of the Draft Family Well-Being Interview protocol (Llewellyn, McConnell & Thompson, 2003) with an independent evaluation of the utility of this protocol for agencies offering family support and services to families of children with disabilities.

Out-of-home placement

This study has provided an excellent opportunity to investigate the factors influencing family well-being and out-of-home placement tendency in families of children with disabilities and high support needs. It has extended and expanded the work carried out by Llewellyn et al. (1996) with families with younger children with disabilities and high support needs. In so doing, the findings that around 6% of families with children with disabilities have taken action to place their child out-of-home (6% in Llewellyn et al., 1999 and 6.2% at the first interview and 17.9% at the second interview in the current study) appear particularly robust. It is striking how the proportion of families who have never considered out-of-home placement decreases substantially from the previous study with younger children to the current study with children of primary school age. In the previous study this proportion was 74.8%. In the current study, the proportion averaged across the two interviews is 62.8% falling from 67.9% at the first interview to 57.7% at the second interview. Concurrently the number of families who remain undecided but considering out-of-home placement rises across both studies and between interview times in study two.

Before too quickly concluding that the rise in families either taking action or considering out-of-home placement is influenced by the passage of time, the professional advice to seek registration of interest by putting the child's name on a waiting list spoken about frequently by families in this study must be taken into account. Further we suggest that while families are thought to be primarily responding to a 'burden of care' rather than an opportunity or positive development in their lives, the increase in requests for out-of-home placement may be an artefact of a service system predicated on an impairment/deficit model and lacking sufficient resources to provide a range of supported family or accommodation options.

Future research needs to explore this system imperative as it appears to be driving families to act and consider placement whether or not they are ready for this. Questions that need to be addressed include how is the topic of out-of-home placement introduced to families and to what effect? How is discussion about placement included in the child's Individualized Education Plan and how is this discussed at the annual review? Are there other imperatives that prompt parents to think about placement before they are ready? If so, what are these and how do they affect parent's decision-making?

We believe there is an urgent need to re-interview the families who participated in this study to determine the type and level of activity focused on out-of-home placement paying particular attention to the influence of professional advice on family decision-making in the intervening time period (2000-2003) and prospectively to 2006 by which time the youngest children will have completed adolescence.

Families moving forward

An alternative formulation to the deficit/impairment model still predominant in family adjustment research would be to acknowledge more strongly a social model of disability. This focuses on identifying and removing the barriers that restrain and impede family life for those families with children with disabilities unable to create and maintain congruent, meaningful and sustainable family routines. Our findings on struggling families reinforce the observation by Grant and Whittell (2000) that decision-making capacity can be taxed when families are "faced with apparently irreconcilable demands" (p. 264). In this instance it becomes even more critical as Grant and Whittell (2000) go on to say that frameworks for assessing parent-carer's needs take into account "those domains of interest which impinge on the different roles carers play within the family and the community" (p. 264). As noted almost a decade ago by Dunst et al. (1993), families should be supported in identifying, clarifying and prioritising needs and aspirations for themselves.

At the same time as giving greater acknowledgement to the diversity of family experiences and in particular recognising the family's perspective on their own situation, attention needs to be focused on the experiences of those families who are thriving. Currently accounts of professional assessment practice suggest that a family's capacity to continue managing is frequently overlooked (Llewellyn, Thompson, & Whybrow, in press). Indeed Knox (2000) and her colleagues in a study of family control in 68 families of children with intellectual disability in the south western region of metropolitan Sydney, noted that when families reported control or partnership status with professionals this was attributed to their own assertiveness rather than from professional recognition and encouragement of their own abilities and strengths.

Service agencies, practitioners, policy developers and other families may have much to learn from hearing and sharing Thriving families' stories, learning about *Sharing* coping styles, and gaining access to information which assists in developing and maintaining family routines that suit all family members. The findings from the present study suggest that this ideal is a long way from being realised for all families with disabled children in metropolitan Sydney and presumably elsewhere. We consider there is an urgent need for a research and development project to develop an empowerment intervention project for families who are struggling based on the strategies used by Thriving families.

In sum, we propose three directions for future research.

1. **Further development, a controlled trial and independent evaluation of the Draft Family Well-Being Interview (Llewellyn, McConnell & Thompson, 2003) protocol**

   In this study we began the task of empirically demonstrating the ways in which families differ in how well (or otherwise) they are doing and why. From this empirical data we developed a draft protocol to assist practitioners to understand a family's daily routine, what is working for the family and what is not, and the factors that support or impinge the family activity of establishing and sustaining a meaningful everyday routines. We believe there is an urgent need to further develop and subsequently conduct a controlled trial of the Draft Family Well-Being Interview protocol (Llewellyn, McConnell & Thompson, 2003) with an independent evaluation of the utility of this protocol for agencies offering family support and services to families of children with disabilities.

2. Follow-up of families to determine the type and level of activity focused on out-of-home placement

In this study we found a substantial increase in the proportion of families considering out-of-home placement by the time of the second interview approximately 12-18 months after the first. One stand-out finding was the influence of professional advice on families' actions and specifically wait-listing their child's name to 'secure' a place in the future. We believe further research is needed into this system imperative as it appears to be driving families to act and consider placement whether or not they are ready for this. We propose a follow-up study with the families who participated in this project to determine the type and level of activity focused on out-of-home placement paying particular attention to the influence of professional advice on family decision-making in the intervening time period (2000-2003) and prospectively to 2006 by which time the youngest children will have completed adolescence.

3. Development of an action research family empowerment project for families who are struggling building on the strategies used by families who are thriving.

In this study we were able to differentiate families along a continuum of sustainability, meaningfulness and congruence in their everyday family routines and we named these families as struggling, doing okay or thriving. Regrettably the literature focuses more attention on those families who are struggling and the 'negatives' in their lives. We suggest that too often service providers also focus their attention on the difficulties encountered by families and neglect the strategies, everyday family routines and resources that families who are doing well bring to bear on their family life. An action research family empowerment project utilising the experiences and stories of families who are doing well, we believe, would provide much needed information to assist struggling families develop and maintain family routines that suit all their family members. Service agencies, practitioners, and policy developers would also benefit from hearing and learning about the other, more positive experiences in the diversity that constitutes everyday family routines in families with disabled children.

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