

**Assessing Family Context of
Children with Disabilities**

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ABSTRACT

If it takes a whole community to raise a child, then supporting a child with a disability necessitates understanding the family and larger social context in which that child is raised. Though many assessment tools have been utilized to evaluate different aspects of family living, few have attempted to capture an integrated ecological perspective of the many factors that impact daily life. Furthermore, many assessment practices fall short of meeting the basic requirements of reliability and validity typically demanded of sound assessment tools. Between the instrument development extremes of no empirical support and exhaustive validation lie many steps towards soundness. In the present research, parents and professionals form an "expert panel" to rate the utility of the Family Context Survey, and to offer recommendations for its improvement. Also, a field study was conducted in which 67 parent participants completed the survey to assess the reliability and validity of this measure for general community use. Implications for family counselling, support service management, and governmental policymaking are discussed.

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CHAPTER 1:

INTRODUCTION AND LITERATURE REVIEW

Families that have children with disabilities live a unique experience of joy, despair, fear, ecstasy, and exhaustion (Barnbill, 2000). The challenges that such families face are numerous, as well as quite unlike those faced by families with "typical" children. From the moment that parents begin to suspect that there is something "different" about their child, their journey of "family life" begins to depart from that of the norm (Cowie, Quinn, Gunning, & Gunning, 1998). They find themselves to be on "foreign ground" where the journey that lays before them is indeed long and fraught with unexpected challenges and disappointments. Ideally, such families will find themselves a professional guide or expert in the disability area challenging their child who can assist them along their journey towards being a happy, healthy, and fully functioning family again.

This journey, however, is far from clear and straightforward. Instead, there are several elements or features of a family's world that must be accurately assessed and effectively addressed if professionals are to deliver the services that the family truly needs. For example, professionals need to clearly understand the interpersonal dynamics within the home, the family's background and history, the ages and personalities of all family members, the degree of marital harmony, and the nature of support that is available from the extended family and community because each of these factors is a determinant of a family's ability to cope and succeed with a having a child with a disability (Mahoney & O'Sullivan, 1992). As such, when assessing any child with a disability, professionals must also assess the unique and dynamic context within which that child lives (Whitehead & Deiner, 1990).

Trying to understand the context of any of today's post-modern families requires recognizing that demographics and family composition change from region to region and home to home. Some families are having fewer children than others, a significant number are getting divorced (or are raising children in blended or step families), and most families now rely on the income of both parents (Wolsh, 1982; cited in Whitehead & Deiner, 1990). Also, families are increasingly being recognized as a fluid and interacting system within themselves, rather than being seen from the more traditional model where the mother was the sole spokesperson and executive director of the family unit (Whitehead & Deiner, 1990). Similarly, the family unit is being seen as a system that interacts with other systems, such as the neighborhood, the school, and the medical community (Deiner, 1987). Clearly, professionals must consider all of these shifting dynamics and unique family needs in their attempt to accurately assess the needs and status of an individual child (Whitehead & Deiner, 1990) if they are to keep their work meaningfully related to the context of each child's family. In light of this increasing complexity and diversity of today's families, there is a growing need for family assessment tools that are sensitive to these unique differences between families.

Theoretical Framework

Several researchers have attempted to accurately portray the experience of families whose child has a disability. Collectively, their research areas cover an array of dynamics and family characteristics from family functioning style (Trivette & Dunst, 1990), to psycho-social stages of coping (Burden, 1991), to satisfaction ratings of social supports (Westling, 1997), to name a few. The central thesis of the present work is that together, these three areas of family assessment can be combined to form a more

encompassing or global perspective of the family. Furthermore, it is suggested here that *only* by combining different perspectives can we hope to create an ecologically valid family-focused assessment tool capable of recognizing the diversity and unique experience of today's families. After all, how can one interpret a parent's assessment of social services without considering the skills and dynamics within the family home? Similarly, how can one fully interpret a family's style of functioning without also accounting for the social support system within which that family must live? In these ways, personal experiences, family dynamics, and the larger social support system are all connected and interwoven, and one's experience of each piece is dependent on his or her experience of the others. This view is consistent with the work of Dyson (1991) who has demonstrated the utility of attaining an "ecological perspective" of the family by showing that a broader perspective of a family, within a social context, yields a more meaningful and valid understanding of the experiences of that family.

To assess this "ecological perspective" a measurement tool called The Family Context Survey was created. It asks over 180 questions related to family background, family functioning style, parental coping, and parental satisfaction with social supports. The Family Context Survey was clinically critiqued by a panel of relative "experts" and subjected to field-testing to determine the reliability and validity of its items and subscales. The following report documents this development and assessment of the Family Context Survey for its eventual use in community counselling and other professional settings.

Assessing Family Dynamics

The professional assessment of family strengths, as well as the attempt to support and strengthen family dynamics, is born out of a short though rich history (Trivette & Dunst, 1990). Much of the pioneering work of Otto (1962, 1963, 1975), Bowman (1983), Curran (1983), and Karpel (1986) have converged to form the major indicators and extensive descriptions of the traits and resources of healthy, well adjusted families.

In terms of assessment *tools* however, there are far more instruments available for assessing family needs (e.g., Fewell, 1986) than for the assessment of family strengths. It has been suggested that this is largely the case because, "until recently, early intervention practices have been primarily deficit oriented and reactive, rather than strength oriented and proactive" (Trivette & Dunst, 1990, p. 17). In an attempt to balance this trend, Dunst, Trivette, and Deal (1988) scoured the family strengths literature to produce a list of 12 major, non-mutually-exclusive qualities of strong families. To best understand these characteristics, the wisdom of Otto (1962) should be noted: "Strengths are not isolated variables, but [rather] form clusters and constellations which are dynamic, fluid, interrelated, and interacting" (p. 80). As such, one should never expect any given family to display all 12 of the qualities, nor should one family be compared quantitatively with another. Instead, family strength assessments can and should be used to help create a picture that represents the primary dynamics of all relationships within a home.

The following list of 12 characteristics, along with their many combinations or clusters, define what Dunst, Trivette, and Deal (1990) call "Family Functioning Style":

1. A belief in and sense of commitment toward promoting the well-being and growth of individual family members as well as that of the family unit.

2. Appreciation for the small and large things that individual family members do well, and encouragement to do better.
3. Concentrated effort to spend time and do things together, no matter how formal or informal the activity or event.
4. A sense of purpose that permeates the reasons and basis for "going on" in both bad and good times.
5. A sense of congruence among family members regarding the value and importance of assigning time and energy to what the family considers its goals, needs, projects, and functions.
6. The ability to communicate with one another in a way that emphasizes positive interactions among family members.
7. A clear set of family rules, values, and beliefs that establish expectations about acceptable and desired behaviour.
8. A varied repertoire of coping strategies that encourages positive functioning in dealing with both normative and non-normative life events.
9. The ability to engage in problem-solving activities designed to evaluate options for meeting needs and procuring resources.
10. The ability to be positive and see the positive in almost all aspects of their lives, including the ability to see crises and problems as an opportunity to learn and grow.
11. Flexibility and adaptability in the roles necessary to procure resources to meet needs.
12. A balance between the use of internal and external family resources for coping and adapting to life events and planning for the future. (p. 18)

Each of these 12 qualities of healthy families can be assessed with the Family Functioning Style Scale developed by Deal, Trivette, and Dunst (1988). This scale uses 26 items and was developed in part, as a family-centered assessment and intervention tool that could be utilized to support and strengthen family functioning. The present research includes all 26 items of the Family Functioning Style Scale as it is a good indicator of

how members within a family work and relate together. This will be particularly important in the assessment of families with disabilities, because it is their "style" of functioning, rather than just their needs, that is often in need of support or validation.

In terms of how professionals should relate to family functioning style, the words of Stoneman (1985) are clear: "Every family has strengths, and if the emphasis is on supporting strengths rather than rectifying weaknesses, chances for making a difference in the lives of children and families are vastly increased" (p. 462). The Family Functioning Style Scale (Deal, Trivette & Dunst, 1988) enables professionals to better assess and understand the unique strengths of any given family.

Initially, the Family Functioning Style Scale can be viewed in terms of its five factors--Commitment, Cohesion, Communication, Competence, and Coping--where each factor describes a relatively unique aspect of family functioning style. Some of the results could be taken to indicate specific topics for family education or training. For example, issues related to coping, competence, or to communication, could be discussed with the family in terms of what they see as contributing to the higher or lower marks that they reported on these scales, perhaps highlighting an appropriate course of intervention. Similarly, low scores on the items that relate to commitment or cohesion may suggest areas for further exploration in family therapy, once those scores have been discussed with the family. Conversely, highlighting and discussing the family strengths or virtues is a good way to reinforce and encourage these skills and abilities that the family already has.

In addition to individual item review, a more rich or complete perspective of the family can be obtained by considering the patterns or "family style" that is revealed

through the constellation of results. For example, when several factors are combined together to form the basic family "style," results may indicate areas of strength or of general family dynamics that merit praise. Alternatively, unproductive patterns may be more clearly recognized which could then be rectified through a collaborative effort. More importantly, families can use the Family Functioning Style Scale to better understand *themselves* (Trivette & Dunst, 1990), and to better communicate with supporting professionals about areas that they feel warrant change. The family benefits by seeing themselves and their strengths more clearly, and professionals gain a more clear appreciation for the interpersonal dynamics within the home.

Assessing Psychosocial Stages of Coping

In addition to a thorough assessment of the family as a unit, there are many important questions to be asked about the psychological well being of the parents of that family. Although thorough psychological assessment of the primary care giving parents would be ideal, it may suffice to determine the level or stage of adjustment that the parent is experiencing. In 1973, Mackeith suggested that mothers of children with disabilities pass through several stages of emotional adjustment as they come to terms with their child's diagnosis. Although these stages have been reworked a number of times since then (Blacher, 1984; Drotar, Baskiewicz, Irvin, Kennell, & Klaus 1975), the phases of shock, denial, sadness and anger, adaptation, and reorganization (Kubbler-Ross, 1969) have become familiar constructs in working with the shock, grief, and loss associated with childhood disabilities.

Robert Burden (1991) has extended the work of Menolascino (1967) and Parkes (1971) to create a transition model of psychosocial stages of coping with stress. In this

model, Burden postulates that parents and families pass through a series of “core family crises” in their adjustment to having a child with a disability. Consequently, the stages of (a) Initial Shock; (b) Realignment of Personal Values; (c) Redefinition of Parental Roles; and (d) Readjustment of Family and Social Roles may all serve as important indicators of the current needs and experiences of families (Burden).

This stage model makes the Psychosocial Coping Scale unlike all other domains in the Family Context Survey. For example, parents are assumed to be in only one stage at a time, forcing scores to be compared between each stage and interpreted as relative endorsement of one stage over the others. Furthermore, as with all developmental models, there is a fundamental assumption that parents progress from one stage to another in the prescribed manner. While this presumed mutual-exclusivity and defined progression of the stages may complicate psychometric validation, it offers a rich and interesting perspective of parent coping.

The most significant benefit of understanding a parent's level of psycho-social development lies in being able to understand the parent's needs in terms of the style of approach that a professional may choose. In other words, assessing the development of psychosocial coping may help professionals to determine which family needs should be addressed first, and in what way. Menolascino (1967), asserted that the difference between a family having a positive resolution to crisis, rather than experiencing the potential negative consequences of that crisis, depends largely on how well the specific treatment needs of the family were met by medical and support professionals. To illustrate, for some families, specific training on how to interact with their child is the essential ingredient to their growth. Whereas for another family, that type of focus on

parenting skills may serve to only increase their fear and anxiety, moving them further away from professional aid! Similarly, deciding *when* and *how* to address the marital issues, or personal values, or perceptions about what a disability may mean to the family can be assisted by understanding the level of psycho-social development, i.e., the specific needs of the parents.

Parents at the "Initial Shock" stage have needs that are quite unlike those of parents at later stages of development. For example, in the Initial Shock stage, parents need to have their experience normalized, they need immediate honest information about the disability and what to do next, clear direction to supports, continuous open-ended consultation with professional supports, coping and relaxation strategies, repetition of information, and early supportive counselling to address emotional reactions and potential biases in perception (Burden, 1991). In other words, it is important to recognize that parents at this stage may be in a literal state of shock perpetuated by their perception of a crisis, and to respond accordingly. As such, the underlying motive for professionals working with families at this stage should be the reduction of crisis and shock through reassurance and directive guidance.

Parents in stage 2 "Realignment of Personal Values" have unique needs as well. At this stage, the initial crisis has retreated leaving the parents feeling "worked over" by this unexpected turn of fate (Burden, 1991). Like many people who face traumatic events, parents with disabled children often question themselves, their lives, their values, and their will to go on (Duis & Summers, 1997). Accordingly, at this personally vulnerable stage, parents often need continuous support from a variety of sources (from professional hands-on support with the child, to a shoulder to cry on), encouragement and support

through the grieving of losses, help in realigning existential values (such as reconnecting with sense of self), and reconnection with meaning and purpose in life which may entail helping them to see a new kind of future (Burden). If the agenda of the first stage was "self-preservation" for the parent, the main agenda here is one of "self-recreation" as parents may need help to find (or re-create) their sense of who they are.

It could be said that parents in stage 3 "Adjustment of Parental Roles" have finished questioning who they are, and now are questioning their abilities as a parent (Burden, 1991). Here, the focus turns back towards the child as parents struggle to learn the new skills necessary to successfully parent a special needs child, and to best manage the demands of the disability. Parents in this third stage need specific advice on how to assist the child's development, reinforcement of parental competence (with all children in home), physical support (workers, care-givers, respite), emotional support (from therapists, support groups, family), reliability of supports, and assisted advocacy for the child's and family's needs. The goal in this stage is to rebuild or reestablish the parents as the "experts" about their children, for their increased confidence and skill will have a profound impact on all aspects of their experience of family life.

In the fourth stage "Adjustment of Family and Social Roles" the family is struggling to function well as a unit and to integrate that team with the larger community and world (Burden, 1991). For many families, this stage is not recognized, or is under-addressed as a significant component of a family's journey towards being healthy, happy, and high-functioning. At this stage, parents need to pull together a network of family and community supports that will meet many of their individual needs, and reduce the draw on expensive social services. For some, this means building more friendships for

everyone within the family. For others, finding effective and cost efficient community services (such as involvement in local church events, youth centers, volunteer organizations) can help to sustain the family and allow their governmental supports to be shared with others in greater need. To do this, families will need support and guidance regarding talking about feelings (and to find the courage to step out into new roles), encouragement to build marriage and family relationships, mixing with others with and without similar problems, advice about how to handle certain social situations and challenges, sustained physical supports (i.e., care providers), and sympathetic and understanding professionals (Burden, 1991). The vision for parents at this stage is "near autonomy." It is presumed that parents not only want to be "free from the social net of support" that has assisted them thus far, but also that they are capable of functioning successfully without (most of) the professional supports. That is, it is believed that if parents can successfully navigate themselves and their family through these four stages, including being able to function well as a family whole and to assert that family back into the community, then the family will require the minimum amount of professional aid and support.

Assessing Satisfaction of Social Supports

In our age of growing fiscal restraint and managed care, the measurement and evaluation of mental health services via consumer satisfaction surveys is becoming an important objective of health care (Stallard, 1996). Moreover, consumer satisfaction is becoming a key determinant of service quality as well as a useful indicator of service outcome (Donabedian, 1992). However, many important issues must be understood prior

to the use of satisfaction instruments. What *is* satisfaction anyway? How can it be accurately measured? And what do the results "mean?"

There are many ways of conceiving how a person's experience of satisfaction might be derived. For example, some researchers (Oliver, 1979) have viewed satisfaction as the gap or discrepancy between one's expectations and actual experience. According to such gap models, satisfaction occurs when the experience is equal to or greater than one's expectations, and dissatisfaction occurs when experience fails to match the expectations. Others, however, suggest that satisfaction is more a function of a multi-dimensional, context specific interaction between several factors meaningful to the individual (Damkot, Pandiani, & Gordon, 1983; Slater, Linn, & Harris, 1982). By these models, many elements such as the physical surroundings, care from support staff, type of service provided, amount of service, procedures performed, and general satisfaction all combine to form the experience of satisfaction.

Whatever the underlying mechanism, people do evaluate their experiences with professional services, and they do have a sense of personal satisfaction or dissatisfaction about those experiences. To that extent, the definition of satisfaction offered by Lebow (1982), that satisfaction is the degree to which a specific treatment gratifies the wants, wishes, and desires of a client will be used here. As such, "satisfaction" as rated by the present Family Context Survey means the extent to which people felt their expectations and specific needs had been met by that particular support service.

There are many ways to ascertain a person's level of satisfaction, from semi-structured interviews and phone conversations, to suggestion boxes, critical incident surveys, and focus groups. However, perhaps the most widely utilized format is the

satisfaction survey. Good surveys incorporate questions about specific areas of satisfaction as well as questions about the person's more general experience (Stallard, 1996). Also, quality surveys make use of open-ended qualitative questions as well as the more traditional quantitative (ranked) questions. In these ways, surveys can produce important information about dissatisfaction as well as highlighting specific areas of contentment.

The work of David Westling (1997) offers a good example of a mental health satisfaction survey tailored to parents whose children have disabilities. In this survey, parents are asked 124 questions that span several content areas such as, "What do parents want their children to learn?"; "Where do parents want their children to go to school?"; "How satisfied are parents with their special education services?"; "How satisfied are parents with social, medical, and other community services?"; and the like. One of the strengths of this particular survey style is the breadth of results and replies that are generated. For example, not only were specific quantifiable results available, such as Westling's finding that 38% of respondents wanted the opportunity to interact with other parents, but also personal content, such as "When our child reaches kindergarten age, the available services will not be satisfactory" were gathered. Clearly, satisfaction surveys such as this are not designed solely to muster support for a particular program or service. Instead, quality satisfaction surveys can come close to meeting their higher aim: To inform service providers about what works and what doesn't work for a set of clients, and to provide the direction and support necessary to effect productive change so that clients get the programs and services that they want and most need.

With permission, many questions from Westing's (1997) Parent's Views Survey Instrument have been modified to meet the particular needs of the present Family Context Survey. For example, many questions about health care are not applicable to the Canadian medi-care system and were either omitted or adapted. Furthermore, additional questions were composed to create a broader perspective about ALL of the support services that a family may be accessing at the time of the survey, rather than relying on the few select areas explored by the Westing survey.

Benefits of a Global Context Assessment Instrument

The potential benefits of combining these disparate perspectives into one "global" assessment tool are numerous. Arguably, the most significant contribution of a more "global perspective" is being able to recognize the reality of a family within a larger context. In other words, with a unifying tool the specific dynamics of a family's experience can be rated (by the family) and understood (by others) within the context of all other dynamics of that family. This is clearly of great value not only in terms of the heightened validity of the responses (i.e., that the multiple perspectives will yield a more "true" depiction of the family experience), but also in terms of complexity. Only by combining multiple perspectives into one tool, can we start to examine the relationships between each point of view. Ideally, being able to understand parts of a family's reality, within the context of other parts, will result in a more complete appreciation of the subtle nuances of each family.

Another benefit of a global assessment tool is that it provides a standard way for parents to communicate with each of the support professionals that may be working with the family. That is, through a single form, parents are able to convey the details of their

"family situation" to the numerous support professionals who all need to understand this similar perspective. For example, a family who completes *one* family context assessment, and delivers copies to their family doctor, child psychiatrist and/or pediatrician, family counsellor, social worker, special education teacher, community agency manager, etc., will save the parents many *hours* of redundant meetings and explanations.

The second advantage in communication is that all stakeholders (i.e., the parents and each support professional) are better able to communicate between each other about the details contained in the survey report. For example, knowing that a particular family has a strong sense of commitment and cohesion would be helpful when that family's social worker, counsellor, and schoolteacher meet together to plan supports and services with the parents. In this way, having only one global assessment report per family will greatly streamline the interdisciplinary communications between professionals by giving them a "common language" and standard reference point from which they can best discuss their unified plan to support each family.

A third benefit of utilizing a global assessment tool pertains to service delivery. By being able to evaluate the effectiveness of each service relative to the others, service managers will be better able to tailor the family support plan to the particular needs of the family. This feature alone could result in substantial savings in mental health care resources while simultaneously delivering a better support service package to each family. In addition, the feedback nature of satisfaction ratings of individual services, when reported within the context of other services and exchanged between service providers, will greatly enhance professional accountability.

In summary, the benefits of understanding a richly complex family context, the time and effort saved via a standard communication system, and the gains from better service management and delivery all combine to support the development and application of a global assessment tool. Accordingly, the Family Context Survey will provide useful information about intricate family dynamics (via family functioning questions), about parental levels and styles of coping (via psychosocial coping-stage questions), and about the parent's satisfaction and areas of dissatisfaction with the support services currently in place. Together, these perspectives will allow "outsiders" to better understand the inner reality of families with disabilities by helping to illuminate the context in which those families live, while assessing our own effectiveness as a community helping to raise their child.

Sound Research

While there has been a recent increase in the use of satisfaction surveys to monitor performance and formulate policy, Chadwick and Stallard (1991) have questioned the role of such surveys and have defined specific criteria that they believe should circumspect survey use. Consequently, before constructing or evaluating a global assessment tool such as the Family Context Survey, it is essential to understand what would constitute "sound research" for a survey of this type. For this, the cautions and recommendations of Stallard (1996) and of Sexton and Thompson (1990) have been carefully considered in an attempt to maximize the reliability and validity of the present assessment tool.

More specifically, Stallard (1996) suggests that all satisfaction questionnaires should be evaluated in terms of their reliability and validity; that surveys should collect

both qualitative and quantitative data; that open-ended questions should be used; and that sources of dissatisfaction be actively sought as well as sources of satisfaction.

Furthermore, Stallard recommends that client characteristics and differing treatment options be noted, as well as the times of service received and survey completion. Lastly, non-respondents should be followed up so as to help ensure that the survey results are representative of *all* service users, not just those that were "satisfied"; and multiple re-testing should become routine so as to permit the evaluation of satisfaction over time. All together, these criteria do help to bolster the strength of a questionnaire. As such, all of these points have been incorporated into the Family Context Survey to the extent possible.

CHAPTER 2: METHODS

Study 1: A Pilot Study for Item Development

The purpose of the pilot study was to assess the content validity of the items to be included in the Family Context Survey. The initial stage of item development consisted of selecting and adapting items from the Family Functioning Style Scale (Dunst, Trivette, & Deal, 1988) and the Parent Satisfaction Survey of Westling (1997) so they would pertain to Canadian families with disabled children. Additionally, items were constructed that would correspond to the four phases of Burden's (1991) Psychosocial Stages of Coping, as well as items related to background information..

For the next stage of item development, an expert panel of parents and professionals rated the suitability of each item and provided important comments and suggestions that were incorporated into the design of the survey. In addition to increasing the content validity of each item, this procedure strengthened the overall utility of the instrument for general community use by ensuring the relevance of each question (Stallard, 1996).

Participants. Twenty-three participants were recruited to form a "Panel of Experts" regarding the lived experience of families with children with disabilities. The Panel consisted of four types of experts: Six parents (from different families), five teachers and/or teaching assistants (specializing in Special Education), six social workers (who support special needs families), and six family counsellors actively working with families with disabilities. Professional subjects were approached via their place of employment, whereas parent participants were approached through their attendance at local parent support groups. Background information was collected pertaining to the

participant's area of expertise, as well as number of years working or living with special needs children, allowing a measure of the degree of "expertise" of these experts to be obtained.

Procedure. Participants were contacted by phone and invited to participate in the research. One copy of the field assessment format of the Family Context Survey was mailed to each participant, with an instruction letter asking them to rate the quality of each item (see Appendix A) and a stamped and addressed return envelope. Follow-up phone calls, to either thank participants or to encourage the completion and return-mailing of the survey, commenced two weeks following mail out.

The questionnaire. A sample survey was constructed that included the background questions of the expert panel participants described above, 16 questions about family background, 26 questions adapted from the Family Functioning Style Scale (Deal, Trivette, & Dunst, 1988), 13 questions pertaining to three additional subscales of family functioning (Advocacy, Marital Harmony, and Sibling Relationships), 12 questions based on stages of psychosocial development (Burden, 1991), and 122 modified questions from Westling's (1997) Parent's Views Survey Instrument regarding satisfaction with social supports yielding 189 items. The content of most items of the field assessment format is listed in Appendix E, though all items were presented in their respective domains and subscales with appropriate titles. Also, to minimize redundancy in evaluating the same five aspects of different service providers, one question rating each of 15 service providers reduced the number of items in the field assessment format of the FCS by 61 questions down to 128.

Analysis and preliminary results. Although the participants in the pilot study were collected using a balanced design that demanded equal representation from each type of expert, there was little reason to suspect that individual participants, or specific types of participants, would respond differently than others. To support this notion, 1-way ANOVAs were conducted between these four rater types to determine significant discrepancies. As only 6 of the 128 items (less than 5%) resulted in significant between-group discrepancies (see Table 2 for item content), support was inferred for collapsing all participants into one group. Accordingly, item means from 23 subjects were assessed for low quality rating scores, i.e., means below 4 on a seven point Likert type scale. As there were no items below 4, all items were deemed acceptable to the expert panel (see Table 3), and were retained for further examination.

Redrafting the Family Context Survey. Following the analysis of Study 1, the Family Context Survey was redrafted to prepare it for field-testing. Changes included two items being dropped due to written feedback from the expert panel (i.e., “How much money do you receive from the government for services?” and “What is your total family income?”), items being revised or reworded based on recommendations of the panel, and items from subscales A through L (see Table 1) being scattered throughout the survey such that no two sequential items from the draft version appear together in the new survey. The organizational structure of the FCS items can be seen from Table 1, while appendices D and E present the FCS Scoring Key and the actual Family Context Survey.

Study 2: Field-Testing The Family Context Survey

As mentioned, the pilot study attempted to explore the questions, “which items are good items, and why?” Having incorporated several of the changes recommended by

the expert panel, the purpose of this second study was to gather preliminary reliability and validity data for the community use of the Family Context Survey. Essentially, the aim was to evaluate the revised survey “in action” by having a group of families with disabilities complete the survey.

Participants. Sixty-seven parents from districts throughout Greater Vancouver participated in this research. Participants responded to a recruitment poster (see Appendix B), delivered via special education classrooms in local schools, agencies that serve people with disabilities, and from parent support groups. Parents were offered an opportunity to win a one time raffle-drawn prize of a \$50 restaurant gift certificate as an incentive for their participation. Families were included only if the parents: (a) had a child with special needs currently living at home, (b) that child had a developmental disability (mild to severe, mental or physical) or marked behaviour disorder, and (c) that child was less than 19 years old. Demographic information regarding these families was assessed via the section of background questions provided at the start of the survey (see Appendix E for item content). Parents responding to the recruitment poster were contacted by phone and invited to participate, and 35 of the 67 families agreed to re-write the survey a second time after a one week break to permit test versus re-test reliability analysis. The Family Context Survey was mailed to consenting families along with a cover letter of basic instructions (see Appendix C) and a return envelope (stamped and addressed). Again, follow-up phone calls to encourage participation began 2 weeks after each survey was mailed.

Description and background information of participants. Of the sixty-seven families that participated in the “field-test” evaluation of the Family Context Survey, the

vast majority (85%) of respondents were biological mothers ($n = 57$), with adoptive mothers ($n = 4$), biological fathers ($n = 3$), and foster mothers ($n = 2$) making up the rest. Nearly 64% ($n = 43$) of participating families reported having two adults living in the home with the disabled child, with 17% having only one adult present and 8% reporting three or more adults. The primary ethnicity of the families was divided as follows: $n = 60$ (90%) Caucasian; $n = 2$ (3%) First Nations; $n = 1$ (2%) Indo-Canadian; and $n = 3$ (5%) reporting Other. Ninety-four percent reported English as the primary language spoken in the home. In terms of education, the single most common educational level reported for mothers and fathers was having attended college or university $n = 33$ (49%) and $n = 23$ (34%) respectively.

As a group, the children with disabilities that parents described had great diversity. The average age was 10, with 46 (69%) boys and 20 (30%) girls. In terms of birth order, most children identified as having a disability were either oldest ($n = 21$, 31%) or youngest ($n = 25$, 37%) in their family. Eleven children were “middle-children” (16%), another eight children (12%) were the “only-child” in their home, and one set of twins. The average age difference between the identified child and his or her closest sibling was 3 years (range 0 to 13 years). The average age for first diagnosis was 3 years ($SD = 3.2$ years), and 42% of parents rated their child’s disability as moderate, 21% said mild, 25% severe, 2% indicated profoundly disabled, and 9% were undesignated.

Strategies for Item Evaluation

Overall, the strategies of item and scale evaluation were conceptually-guided approaches to instrument development and evaluation. As such, the utility of these assessments is emphasized for use in community settings. The analytic procedures are

summarized here to provide an overview of the strategies utilized for item evaluation. Following data collection, all missing scores in the Family Functioning Domain and the Psychosocial Coping Domain were replaced with mean item values to enable all subjects to be utilized in subscale reliability analyses. No replacements were made in the missing data for the Satisfaction domain. In the Principle Components Analyses (PCAs) reported below, oblique rotations were examined in comparison to orthogonal rotations where appropriate. Furthermore, it should be noted that confirmatory PCA was not possible due to the small sample size, as such all Principle Components Analyses were considered exploratory in nature.

The Family Functioning Domain was evaluated in six distinct steps. Initially, internal consistency estimations (alpha coefficients) provided reliability assessments of each of the five subscales (A–E) of the Family Functioning Style Scale (Dunst, Trivette, & Deal, 1988) and their composite score. Next, items in the three proposed additional subscales (F - Marital Harmony, G - Sibling Relationship, and H – Advocacy) were subjected to item-level Principle Components Analysis (Varimax rotation) to examine the coherence of these three subscales. Thirdly, item loadings on each of these subscales (F, G, and H) were assessed for internal consistency, and correlations of subscale scores with the Family Functioning Domain Grand Score were computed (subscales A–H transformed to represent one composite percentage score; see item M in Appendix D). Fourthly, Principle Components Analysis was also conducted on subscales A through H to determine whether subscales F, G, and H loaded on the first component to the same degree as did subscales A–E. Fifthly, concurrent validity checks were conducted by correlating grand scores for the Family Functioning Domain (subscales A–H) with

participants' estimation of their families' overall functioning level as a single item score. Lastly, test-retest reliability correlations were conducted on all eight subscales as well as the estimated overall Family Functioning. The objective of this six step approach was to establish subscales A through E (provided by Dunst et al., 1988) as a benchmark for the assessment of F, G, and H, then to evaluate the new group of eight subscales for their internal validity and reliability as a single domain or cluster.

The Psychosocial Coping Scale (subscales I–L) was assessed through a four-step process. Initially, item-level Principle Components Analysis was used to explore the correlational structure of the items. It should be noted that the Psychosocial Coping Scale was formulated around a stage model in that the item content for each stage was intended to reflect aspects of a person's stage specific experience rather than reflecting a specific underlying construct. Item scores, therefore, may or may not cohere into factorially distinct subscales. Nevertheless, this possibility was examined. Next, internal consistency estimations (alpha coefficients) provided reliability assessments of each subscale. Thirdly, alpha coefficients were calculated for adjacent pairs of stages (1 with 2, 2 with 3, and 3 with 4), as well as for stages 1 with 4, as an alternative investigation of item structure. Fourthly, concurrent validity was evaluated for each stage via Pearson correlations with conceptually related items from other sections in the survey. For this procedure, conducting only the anticipated correlations, rather than calculating all possible relationships, minimized experiment-wise error rates.

The Satisfaction domain was evaluated for test-re-test reliability for each subscale. Furthermore, subscales P, Q, and R were assessed for internal consistency. For the Satisfaction Domain Grand Score, scores for all applicable items were transformed to

represent one composite percentage score (see item X in Appendix D) which was then compared with the participants' overall estimation of their satisfaction with the supports they receive as a measure of concurrent validity.

CHAPTER 3: RESULTS

Means and standard deviations for all subscales and other key variables are listed in Table 4, while Table 5 lists all correlations between these variables. The mean total scores for the Family Functioning Domain and the Satisfaction Domain were 64.7 ($SD = 5.65$) and 35.5 ($SD = 7.42$) respectively, giving a rudimentary benchmark for nomothetic comparison. The scorings for these various scales are presented below.

Family Functioning Style

The Family Functioning subscales (Dunst, Trivette, & Deal, 1988), yielded poor to adequate internal consistency in this sample: Commitment = .64, Cohesion = .58, Communication = .76, Competence = .61, and Coping = .51, with an overall alpha of .90.

With the small sample obtained, principle components analyses (PCAs) were conducted for tentative item analyses. As anticipated, PCA on the items that formed the Marital Harmony, Sibling Relationships, and Advocacy subscales yielded three main factors (see factor loadings matrix, Table 6), suggesting that the items in two of these subscales provide adequate assessment of the underlying constructs. The third factor (corresponding to the Advocacy subscale items) was less concise with only two of the four items loading adequately on this component. Notwithstanding this weak item cohesion of the Advocacy subscale, the subscale scores were retained for further evaluation. Alpha coefficients for these subscales were .77, .87, and .50 respectively, and their correlations with the Family Functioning Style Scale (Subscales A–E) were sufficiently strong (.49, .48, .42) to include them in this domain. Next, a scale-level PCA suggested that the Marital Harmony subscale loaded on the first component to the same degree as did subscales A-E without the F, G, and H scales included (see Tables 7 and 8).

The second component, defined by Coping and Sibling Relationships, correlated strongly with the first, $r(65) = .52$, supporting the preliminary use of the total score for this domain. As such, all eight subscales (A through H) were included in the new Family Functioning Domain Grand Score, which yielded an overall alpha coefficient of .91. The calculated Grand Scores for the Family Functioning Domain correlated moderately with participant's estimates of Family Functioning levels for their family, $r(66) = .31$. Lastly, the subscales of the Family Functioning Domain, and the single item estimate of Overall Family Functioning yielded adequate test-retest reliability correlations in this sample: Commitment = .76, Cohesion = .78, Communication = .79, Competence = .68, Coping = .71, Marital Harmony = .48, Sibling Relationships = .80, Advocacy = .89, and Estimated Functioning = .78. This suggests that most of the subscale scores are relatively stable across short periods of time.

Psychosocial Stages of Coping

For the stages of psychosocial coping (subscales I-L), PCA was conducted as a tentative exploration into the possibility that patterns of item intercorrelations would reflect the stages, but no simple factor structure was observed (see Component Loadings Matrix in Table 9). The items were assigned to each of the four stages on a theoretical basis, yielding internal consistency reliabilities of .33, .66, .55, and .48. Alpha coefficients for items in adjacent stages 1 with 2, 2 with 3, and 3 with 4 (.67, .75, and .68 respectively), versus items in stage 1 with stage 4 (.43), reflected the high inter-stage correlations typical of stage-model scales, and support the assumptions of stage differentiation and progression. Stage 1 (Crisis of Shock) did not demonstrate the anticipated inverse correlation with Length of Time Since First Assessment, $r(65) = -.05$,

$p = .35$, one-tailed test. However, Stage 2 (Crisis of Personal Values) did have inverse relationships with Commitment, Pearson's $r(65) = -.29$, $p = .01$, one-tailed test, with Competence, Pearson's $r(65) = -.35$, $p = .01$, one-tailed test, and with the coping subscale of the Family Functioning Domain (subscale E), Pearson's $r(65) = -.51$, $p < .01$, one-tailed test. Stage 3 (Crisis of Parental Roles) was inversely correlated with item Y, Estimated Overall Satisfaction with Supports, Pearson's $r(65) = -.25$, $p = .02$, one-tailed test). Stage 4 (Crisis of Family & Social Roles) was positively correlated with item 177 Building a supportive Team of the Future Directions Domain, Pearson's $r(65) = -.22$, $p = .04$, one-tailed test, although the four other anticipated relationships (170 Social Skill Development, 174 Building Friendships, 181 Finding Care Workers and Length of Time since first assessment) were not significant. Family-wise error rates would only predict one significant result for this domain based on chance, so the overall pattern suggests that substantive relationships have been obtained.

Satisfaction with Social Supports

The subscales of the Satisfaction Domain yielded adequate test-retest reliability correlations in this sample: Educational Setting = .87, Home Setting = .66, and Support Providers = .91. The overall test-retest correlation for the Satisfaction Domain Grand Score was .87, suggesting that this domain demonstrates adequate reliability as well. Furthermore, alpha coefficients for the first two subscales were .83 ($n = 43$), and .76 ($n = 19$) respectively, indicating good internal consistency. The calculated Grand Scores for the Satisfaction Domain (item X) correlated adequately with participant's estimations of these levels for their family (item Y), $r(65) = .53$, suggesting that this single item may be a valid representation of the composite score.

Satisfaction scores for all service providers were divided into their respective derived scales of Time, Availability, Quality, Importance, and Competence. As can be seen in Table 4, the pattern of ratings suggests that Quality, Importance, and Competency of service providers generally scored higher than did ratings of Time and Availability. As expected, ratings of Importance of the service provider scored higher than the four aspects of service delivery. All five of these subscales were correlated with the Satisfaction Domain Grand Score, $r(65) = .88$, $r(65) = .90$, $r(65) = .94$, $r(65) = .78$, and $r(65) = .87$ respectively.

In summary, evidence was obtained for each section of the FCS that provided preliminary support for the interpretation of scores in light of the constructs utilized to guide the instrument development. More specifically, concurrent validity, content validity, and factor analysis have established initial construct validity for the Family Context Survey.

CHAPTER 4: DISCUSSION

Validity and Reliability of the Family Context Survey

This study was conducted for the purpose of designing and providing preliminary evaluations of an information-gathering tool intended for use in community counselling settings. Items were developed to assess family functioning style, parent coping, and parent satisfaction with social and professional supports. A panel of key informants was then asked to rate the quality of each proposed item for its suitability in assessing the family context of children with special needs. Then, once minor revisions had been made, the survey was field-tested with a sample parents who have children with disabilities.

The panel of 23 experts made valuable contributions to the item development FCS. All combined, the years of experience of working or living with children with disabilities exceeded 235 years! The key informants' support for each item suggests strong content validity of those items. If an item was appropriate for evaluating families with disabilities, or not, the parents, special needs teachers, social workers, and family counsellors were able to tell. In fact, after viewing the survey, the panel rated the importance of the FCS to their work with children to be 5.71 ($SD = .99$) on a 7-point scale. Additionally, because each member of the panel was encouraged to provide specific written feedback about any notable items, subtle shaping of the FCS was accomplished by the panel, making the pilot study a powerful test and testament to the suitability of the FCS.

Although it was challenging to recruit 67 parents to complete the instrument, field-testing the Family Context Survey added substantially to its validity and reliability. Furthermore, while the sample size was smaller than desired, it was sufficiently large

enough to permit statistical evaluations. The participants represented a diverse sample of the special needs community which ensured that patterns or response biases that may be characteristic of one type of family were balanced by the responses of others. However, this dynamic may actually have limited the performance of the FCS by allowing families with more severely disabled children, or families with greater levels of stress or dysfunction, to be masked by families with more stable situations. Because two thirds of the sample rated the severity of their child's disability as mild or moderate, the family functioning and personal experiences of parents whose children have severe or profound disabilities may be underrepresented here.

The items in the Family Functioning Domain performed well by revealing adequate validity at the item level as well as strong reliability in test-retest evaluations of its subscales. The relatively lower alpha coefficients in some subscales indicate that further item refinement is in order. Specifically, the subscales of Cohesion, Competence, Coping, and Advocacy may need to be reworked to create stronger internal consistency. Furthermore, item q20 ("We have good friends and family who help us to succeed as a family") should be reworded to better reflect its intended role in the Advocacy subscale. Likewise, q61 ("My partner and I spend quality time together away from children") should be reworded to better reflect the Marital Harmony component as intended. While there is some indication that the five subscales provided by Dunst, Trivette, and Deal (1988) were an appropriate benchmark for the assessment of the three proposed new subscales (F, G, and H), the overall functioning of the items in this domain should be further refined to create more independence between their respective subscales.

The items in the Psychosocial Coping Domain reflected characteristics consistent with a stage-model framework. In other words, unlike other trait-model domains, items in the Psychosocial Coping Domain represent the experiences of people at each stage of development, rather than universal qualities or dimensions. Consequently, items are often highly intercorrelated between stages as much as within. Responses from people in transitional stages are often difficult to assess and interpret with questionnaire methods.

Despite these conceptual and psychometric challenges, the last three subscales of the Psychosocial Coping Domain showed promising concurrent validity within the survey as a whole, however there was less support for Stage 1–Crisis of Shock. Additional efforts to assess the validity of these four stages will greatly assisted the interpretation of the correlation findings. As such, finding some of the anticipated relationships with other variables does imply that these stages represent the underlying experiences predicted. Further item and stage development, as well as convergent validity measures are recommended for future enhancement of this domain.

The Satisfaction Domain performed adequately, showing good test-retest reliability in its three subscales, as well as strong internal consistency of its Educational Setting and Home Setting subscales. However, methodologically, the Service Provider subscale yielded low response rates as a sample of families of children with less severe disabilities. This occurred because this subscale was composed of the 15 different professionals being evaluated. Given the diversity of the child and family needs represented in the present sample, there was little to no consistency in terms of having a shared profile of service providers. This meant that each provider was ranked as “Not Applicable” by at least one participant (and likely several participants) in the sample. If

future samples reflect children with more severe disabilities, and therefore, required more professional services, then one may wish to evaluate the internal consistency of this subscales for that population. Overall, this domain provides reliable and valid information about how parents perceive their respective community supports.

Together, the pilot study and the field evaluation serve as the first of several steps in the process of establishing the Family Context Survey as an empirically grounded assessment tool. While further steps towards this goal may still be taken, the present work has revealed the FCS to have adequate empirical support to warrant its preliminary use and further investigation.

Theoretical and Practical Implications

Finding the FCS to be an appropriate and empirically validated assessment tool creates several important implications for the counselling field. Firstly, it suggests that the FCS is an answer to the growing need for mental health professionals to use psychometrically defensible instruments. This implication becomes particularly poignant when one considers the finding that less than 10% of the more than 300 child-focused preschool measures actually have documented reliability and validity (Sexton, 1990). In other words, while the present project may reflect only preliminary advances towards establishing the FCS as sound, it provides far more support for its use than do most assessment tools. As such, community agencies are well justified in selecting the FCS as part of their assessment arsenal, as it has demonstrated preliminary soundness in this capacity.

Secondly, because the FCS has been designed to assess an ecological or contextual perspective of a family, it is more consistent with wrap-around integrated care

philosophies emerging from the social service sector. For example, through the Family Functioning Domain subscales, counsellors gain a systemic view of how the family works as a team by revealing the specific styles that characterize all relationships within that family unit. This understanding gains further validation and refinement when added to information about the coping styles of the primary caregiver as leader of the family team, as provided by the Psychosocial Coping Domain. In other words, the functioning of the family-team is reflected in the coping of the parents. Then, through the Satisfaction Domain, an impression can be formed about how the family-team interacts with the larger community of support providers. Also, by reviewing the profile of satisfaction ratings and integrating this with the information provided in the Future Decisions Domain, counsellors are able to identify which issues in the child's life, as well as within the support system, are most relevant to the family's success and the child's well being. Finally, when the FCS is used repeatedly with the same family, it will help the family counsellor to better recognize changes in the family system, and thereby inspire change in the services being delivered.

It is precisely this contextual perspective, where each specific element can be understood in relation to other important factors, that makes the Family Context Survey unlike other assessment tools. Beyond the mere assessment of family functioning, or parent coping, or satisfaction, the Family Context Survey puts each of these assessments into the context of the others (e.g., Burden, 1991; Dunst et al., 1990; Westling, 1997). In this way, family functioning can be seen as a product of a parent's psychosocial adjustment to family stress, as well as a correlate of how well supported that family is by the professional service providers in their community. Similarly, the parent's coping can

be recognized as being a function of the family's characteristics, and their support from others outside the home. And by extension, a parent's satisfaction with professional supports is equally related to that person's coping and family functioning. In these ways, the FCS surpasses the isolated assessments of dynamics related to children with disabilities, and provides a unique three-dimensional perspective not possible with any one of the three assessment tools on its own.

There are also many therapeutic advantages to each family that completes the FCS as part of their intake and case development process with any service-providing professional. For instance, families will benefit from participating in the survey by gaining more insight into the elements of their own family functioning and levels of support. Such families will also be able to compare their level of functioning, satisfaction, and service to that of other families in their community, helping each family to better understand themselves in relation to others. Lastly, patients will be better able to justify the specific services, or service provider changes, they need by being able to identify which services or providers are important and useful or not.

For agencies and professional offices providing front-line support services, much can be learnt in terms of what specific features of the service are deemed most valuable to families. For example, a sufficiently large sample of client families could all report low ratings of timeliness, availability, quality, or competency for any given service. If this were combined with the information that the service is important and that their overall satisfaction is low, it would provide substantial evidence for restructuring the service to address the problem. Another service delivery implication relates to identifying families that are functioning well or adequately with the services being delivered and which are

not. This screening function of the FCS will become more and more valuable as service providers become increasingly concerned about outcomes and program efficacy. A further implication addresses the question of “where specifically should future services be targeted to best meet the needs of a given community of families?” In other words, by studying group responses to the FCS, an agency may discover services or family needs that are not being offered or addressed via the current service delivery model. In this capacity, the FCS could help steer strategic planning and future programming development, helping to ensure that services are directly tied to the identified needs of the clients being served.

For support-service management and governmental policymaking, invaluable information could be provided in terms of identifying which social supports are most valued by specific types of families, and which combinations of supports best assist family functioning. Although this information could be used to defend budget reductions, it could just as easily be used to secure the appropriate allocation of resources identified by a community as valuable. Another implication related to financial management is that the FCS could be used to identify *types* of families that could withstand a reduction in level of service being provided, as well as those who are in desperate need of more specialized family supports. Obviously, families and communities should not lose or receive funding or support services based solely on the numbers presented in a survey. Instead, the implications listed here are raised with the hope of inspiring an ethical and open way for services to be best matched with human needs. Furthermore, limitations that reflect the tentativeness of this partially established instrument should be considered before and during the use of the FCS in community settings. That is, until further

development and evaluation, data from the FCS should be used with care to avoid over interpretation. Similarly, community agencies, government bodies, and academic researchers should guard against premature generalizations and comparisons based on data from the FCS.

Even with the aforementioned cautions in mind, the potential benefits to individual families, counsellors, agencies, and governments form a compelling argument for the widespread application of the Family Context Survey. Initially, to enable this vision, further instrument development and assessment are in order to better refine the item, subscale, and domain total scores. Secondly, survey application and scoring protocols should be developed to facilitate wider access and use of the FCS. Thirdly, each of the 15 types of service providers can be made aware of the FCS and its unique applications to their respective professions. Next, the mental health community will need to determine how to best initiate and regulate the use of the FCS with individual families, as well as how to disseminate the FCS report to the appropriate support providers and stakeholders. Through these actions, the FCS could begin to reach its potential as a multi-disciplinary, information sharing catalyst, inspiring busy professionals from many diverse professions to take an interest in, and exchange ideas about, the unique context surrounding the families they serve.

Even without all of these applications being realized, the FCS should be put to use in counselling agencies and professional mental health offices as a routine part of the intake and on-going client, outcomes monitoring, and program evaluation processes. As such, counsellors should endeavor to routinely reassess family context every four to six months for each family they serve. Furthermore, additional professional development in

the areas of family systems theory, family functioning, and crisis theory would greatly assist counsellors using the FCS to ensure they are getting the largest therapeutic advantage from their efforts.

Limitations of the Study and Future Research

Some of the shortcomings of the present research include the relatively small sample size, as well as the non-balanced design in subject selection. This impacted many of the analyses by compromising the power of the statistical assessment, and by limiting the results available regarding the comparative influence of background variables that were not well represented. As such, future research in this area would benefit greatly from having more participants and from ensuring that each of the disability types and several other background variables are represented equally so that specific comparisons between background variables is possible.

In terms of survey design, many other topics could also have been incorporated into the Family Context Survey that were not. For example, additional subscales could have been designed to provide insight into other family dynamics such as drug and alcohol use, employment and socioeconomic status, recent critical stressors, parenting aptitude, etc. These and other topics would further expand the scope of the survey, and provide an even more detailed understanding of the family context that surrounds the child with a disability.

Another limitation of this project is its heavy reliance on quantitative measurement scales. While this may have been essential for empirical validation, there is clearly more work needed to evaluate the link between parents' qualitative experience of family, and their responses on the FCS. Furthermore, the FCS contains a fourth domain,

the Future Directions Domain, the evaluation of which was deemed beyond the scope of the present project. While it greatly assisted the cross validation of conceptually related subscales in the present study, the items in this fourth domain remain to be empirically substantiated.

Conclusion

Although social values are shifting and moving towards appreciating the interweave between any family and its larger social context, a corresponding sophistication of how the mental health community assesses family complexity has yet to emerge. Such advances in social service process are particularly relevant to families with children who have disabilities as these families, more so than many others, are highly connected to and reliant on professional community supports. This situation has created the need for assessment tools that sensitively evaluate the family and community context that surrounds a child with a disability. In the present study, the Family Context Survey was rigorously evaluated by an expert panel to determine its suitability, and was then subjected to field-testing to assess its functionality in serving this need. Overall, the Family Context Survey has demonstrated preliminary reliability and validity as an assessment tool, and has adequately justified its use and further evaluation in the counselling setting. In addition to these psychometric qualities, the FCS has revealed its central contribution by highlighting three interrelated key dimensions of the family experience of childhood disabilities. As society demands more evidence-based and empirically grounded practices from the mental health profession, as well as thorough measures of program efficacy and client contentment, it is hoped that the Family Context

Survey will be further substantiated as a sound way to assess the many family and community dynamics that surround children with disabilities.

REFERENCES

- Baker, B., & Brightman, A. (1994). Steps to independence: A skills training guide for parents and teachers of children with special needs. Baltimore: Brookes.
- Barnbill, (2000). Book notes: A review of 'Something's wrong with my child' by Harriet Wallace Rose and Charles C. Thomas. Intervention in School & Clinic 35(3), 190-192.
- Bischoff, L., & Tingstrom, D. (1991). Siblings of children with disabilities: Psychological and behavioural characteristics. Counselling Psychology Quarterly, 4(4), 311-322.
- Blacher, J. (1984). Sequential stages of parental adjustment to the birth of a child with handicaps: Fact or artifact? Mental Retardation, 22, 55-68.
- Bowman, T. (1983). Promoting family wellness: Implications and issues. In D. Mace (Ed.), Prevention in family services: Approaches to family wellness (pp.39-48). Beverly Hills, CA: Sage.
- Bowman, T (1999). Shattered dreams, resiliency, and hope: 'Restorying' after loss. Journal of Personal & Interpersonal Loss 4(2), 179-194.
- Burden, R. (1991). Psycho-social transitions in the lives of parents of children with handicapping conditions. Counselling Psychology Quarterly, 4(4), 331-344.
- Chadwick, R., & Stallard, P. (1991). Consumer evaluation: A cautionary note. Clinical Psychology Forum, 34, 2-4.
- Cowie, K., Quinn, K., Gunning, M., & Gunning, K. (1998). School/home issues related to grief and loss within the families of disabled students: A systems approach. Family Journal, 6(2), 141-147.

Curran, D. (1983). Traits of a healthy family. Minneapolis, MN: Winston.

Cunningham, S. (1999). Working with children with disabilities, Volume I: The fundamentals of parenting and professional care. Manuscript not yet in press.

Damkot, D. K., Pandiani, J. A., & Gordon, L. R. (1983). Development, implementation, and findings of a continuing client satisfaction survey. Community Mental Health Journal, 19, 265-278.

Deiner, P. (1987). Systems of care for disabled children and family members: New paradigms and alternatives. Marriage and Family Review, 11(1/2), 193-211.

Donabedian, A. (1992). Quality assurance in health care: Consumers' role. Quality in Health Care, 1, 247-251.

Drotar, D., Baskiewicz, A., Irvin, N., Kennell, J., & Klaus, M. (1975). The adaptation of parents to the birth of an infant with congenital malformation: A hypothetical model. Pediatrics, 56(5), 709-717.

Dunst, C. J., Trivette, C. M., & Deal, A. G. (1988). Enabling and empowering families: Principles and guidelines for practice. Cambridge, MA: Brookline.

Duis, S., & Summers, M. (1997). Parent versus child stress in diverse family types: An ecological approach. Topics in Early Childhood Special Education, 17(1), 53-74.

Dyson, L. L. (1991). Families of young children with handicaps: Parental stress and family functioning. American Journal on Mental Retardation, 95, 623-629.

Fewell, R. R. (1986). The measurement of family functioning. In L. Bickman & D. Weatherford (Eds.), Evaluating early intervention programs for severely handicapped children and their families (pp. 263-307). Austin, TX. PRO-ED.

Hornby, G., & Seligman, M. (1991). Disability and the family: Current status and future developments. Counselling Psychology Quarterly, 4(4), 267-272.

Karpel, M. (Ed.). (1986). Family resources: The hidden partner in family therapy. New York: Guilford.

Kubler-Ross, E. (1969). On death and dying. New York: Macmillan.

Lester, A. (1995). Hope in pastoral care and counselling. Louisville, KY: Westminster/John Knox.

Mackeith, R. (1973). The feelings and behaviours of parents of handicapped children. Developmental Medicine and Child Neurology, 15, 524-527.

Mahoney, G., & O'Sullivan, P. (1992). The family environments of children with disabilities: Diverse but not so different. Topics in Early Childhood Special Education, 12(3), 386-403.

Menolascino, F. J. (1967). Parents of the mentally retarded: An operational approach to diagnosis and management. Journal of The American Academy of Child Psychiatry, 7, 589-602.

Margalit, M., & Ankonina, D. (1991). Positive and negative affect in parenting disabled children. Counselling Psychology Quarterly, 4(4), 289-300.

Oliver, R. L. (1979). Product dissatisfaction as a function of prior expectation and subsequent disconfirmation: New evidence. In: R. L. Day & H. K. Hunt (Eds.), New dimensions of consumer satisfaction and complaining behaviour. Illinois: Indiana University, 66-71.

Olsen, S. (1999). Support, communication, and hardiness in families with children with disabilities. Journal of Family Nursing, 5(3), 275-292.

- Otto, H. (1962). What is a strong family? Marriage and Family Living, 24, 77-81.
- Otto, H. (1963). Criteria for assessing family strengths. Family Process, 2, 329-334.
- Otto, H. (1975). The use of family strength concepts and methods in family life education: A handbook. Beverly Hills, CA: Holistic.
- Parkes, C. M. (1971). Psycho-social transitions: A field for study. Social Science and Medicine, 5, 101-115.
- Romanoff, B., & Terenzio, M. (1998). Rituals and the grieving process. Death studies. 22(8), 697-712.
- Sexton, D., & Thompson, B. (1990). Measurement characteristics of the inventory of parent experience scales. Topics in Early Childhood Special Education, 10, 36-49.
- Shapiro, E. (1994). Grief as a family process: A developmental approach to clinical practice. New York: Guilford Press.
- Slater, V., Linn, M. W., & Harris, R. (1982). A satisfaction with mental health care scale. Comprehensive Psychiatry, 23, 68-74.
- Stallard, P. (1996). The role and use of consumer satisfaction surveys in mental health services. Journal of Mental Health. 5(4), 333-349.
- Stoneman, Z. (1985). Family involvement in early childhood special education programs. In N. Fallen & W. Umansky (Eds.), Young children with special needs (2nd ed.) (pp.442-469). Columbus, OH: Merrill.

Trivette, C., & Dunst, C. (1990). Assessing family strengths and family functioning style. Topics in Early Childhood Special Education, 10(1), 16-36.

Walsh, W., & McGraw, J. (1996). Essentials of family therapy: A therapist's guide to eight approaches. Denver, CO: Love.

Westling, D. (1997). What parents of young children with mental disabilities want: The views of one community. Focus on Autism and Other Developmental Disabilities, 12(2), 67-80.

Whitehead, L., & Deiner, P. (1990) Family assessment: Parent and professional evaluation. Topics in Early Childhood Special Education, 10(1), 63-77.