The Family Inventory of Resources for Management: Content validity and utility among mothers living at home with adult sons/daughters who have developmental delays.

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THE FAMILY INVENTORY OF RESOURCES FOR MANAGEMENT:
CONTENT VALIDITY AND UTILITY AMONG MOTHERS LIVING AT HOME
WITH ADULT SONS/DAUGHTERS WHO HAVE DEVELOPMENTAL DELAYS

by

Elizabeth Jane Hall

B.Sc.Hons. Memorial University of Newfoundland, 1993

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Submitted to the Faculty of Graduate Studies
through the Department of Psychology
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Requirements for the Degree
of Master of Arts at the
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1995
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ABSTRACT

The current study explored the use of internal and external resources, that were identified as helpful, by mothers who had adult sons/daughters with developmental delays living at home. Semi-structured interviews were conducted with 28 mothers (ranging in age from 47 to 79 years) and analyzed qualitatively using a "constant comparative" approach. Ten categories of resources emerged from the analysis namely, Community Agencies, Employers, Family Members, Friends/Neighbours, Health Professionals, Husbands, Informal Networks, Personal Resources, Religious Faith, and Schools. However, a correlational analysis revealed that the only category significantly related to the Family Inventory of Resources for Management (FIRM), a test designed to measure resource use, was the category Religious Faith. Instead, the categorization system appeared to be better suited to the Family Crisis Oriented Personal Evaluation Scales (F-COPES). Resource use was not related to the age of the mothers, or the behaviour problems of their adult offspring, rather, it appeared that current resource use was determined by previous resource availability. In addition, there was evidence that mothers' reports of high levels of stress were related to increased interactions with friends and neighbours.
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CHAPTER I

INTRODUCTION

Traditionally, we have not been concerned with the provision of long-term care for adults with developmental disabilities. In particular, two reasons for this oversight can be identified. First, children with handicaps were particularly vulnerable to disease and often died before they reached adulthood (Jennings, 1987; Seltzer & Krauss, 1989). Secondly, children with disabilities formed an "invisible" part of society. They were habitually segregated from the general population, either via institutionalization or by a protective and/or embarrassed family (Cameron, 1979; Jennings, 1987; Wikler, 1986a). These families, afraid of stigmatization, would often limit the contact that a family member with a disability could have with the external world. In addition, the families who did provide care within the home for such a family member often had no community education or work programs available to them (Cameron, personal communication, 1995). As a result, there were few opportunities for the person with a handicap to participate in community activities. Thus, if the person who had a handicap was particularly resilient and reached adulthood, s/he grew old within a confined and isolated environment, out of sight and mind from the general population.

However, with the current emphasis of public policy on
deinstitutionalization and the provision of community oriented care, accompanied by the improvement of medical and nutritional knowledge, there has been a marked increase in the absolute and "visible" number of adults with developmental delays in our society (Jennings, 1987). The exact number of Canadian adults who are developmentally delayed is unknown. However, a government survey in 1991, which utilized the World Health Organization's definition of disability, namely "any restriction or lack (resulting from impairment) of ability to perform an activity in the manner or within the range considered normal for a human being," identified approximately 4 million Canadians or 15% of the population as having some level of disability (Statistics Canada, 1992, pp. 1 - 2). Of these, 93.7% resided in private households (Statistics Canada, 1992, p. 1). Similarly, the results from a study conducted in the United States, which specifically examined the living arrangements of 120 adults who were developmentally delayed, revealed that three years after graduating from a public school program, 94% of the adults were living at home with their parents (Stanfield, 1973).

Clearly, there is now a need to examine the effects that providing long-term care, within the home, for an adult son/daughter with a developmental delay has on the family system, and more specifically the primary caregiver, usually the mother. While the results from some studies indicate
that providing care in this manner is sometimes stressful, only a few studies have examined these effects in any detail (Slater & Wikler, 1986). In particular, most researchers have failed to investigate the role that other factors, such as resources, play in determining the degree of stress that caregivers, providing care to adult off-spring, experience. As such, this study will address the paucity of research in this area. Specifically, it will examine the availability and use of resources by mothers who are providing care, within the home, to their adult sons/daughters with developmental delays.

Previous research in families where there was a child (not adult) who had a developmental delay has focussed primarily on events during the early stages of the family life cycle, namely events surrounding the child’s birth and during the child’s school age years. As such, this research has examined issues such as initial parental reaction to the discovery that their child was handicapped (Cameron, 1979; Drotar, Baskiewicz, Irvin, Kennell, & Klaus, 1975), mothers’ adaptations to their child’s handicap (Wallander et al., 1989), and the delineation of parental differences in coping and coherence (Margalit, Raviv, & Ankonina, 1992).

Some research examining the effects of caregiving in parents with adult off-spring has been conducted. However, the focus has been on reciprocal spousal support or the care that adult sons/daughters provide to their parents, rather
than the on-going role of parents as caregivers to their adult off-spring (Jennings, 1987). According to Adams (1968), most parents provide more help to their adult progeny than they receive from them. Aldous (1987) reports that numerous social problems such as divorce, drug addiction, and unemployment, have forced many people into re-adopting a parenting role with their adult sons/daughters. Parents of adult off-spring who have developmental delays are somewhat different however, as they have never relinquished a caregiving role with their son/daughter. Rather, they are faced with the issue of "perpetual parenthood" (Jennings, 1987).

The results from the few studies that have examined the latter stages of the family life cycle among families of children with developmental delays indicate that, in general, as noted earlier, family life becomes more stressful as the children get older (Farber, 1986; Slater & Wikler, 1986; Wikler, 1986b). For example, Bristol and Schopler (1983) examined families with autistic children and found that older children (ranging in age from 9.5 to 19 years) caused more problems than younger ones (aged between 4 to 9.5 years), parents of older children were more likely to be experiencing burnout, and fewer support systems existed for parents with older children. Similarly, Suelzle and Keenan (1981) also reported the presence of fewer support systems for parents of older children (aged 19 to 21
years old) who were handicapped. These support systems are especially important because they form part of the resource network available to the family. Indeed, the declining availability of resources among parents of older children who have handicaps is an issue that will be addressed in this study.

Moreover, these problems are further heightened by other concerns that parents have to struggle with, and eventually resolve, surrounding their son’s/daughter’s transition into adulthood and middle-age. For example, parents have to decide on an appropriate residence for their off-spring, deal with issues of their son’s/daughter’s sexuality, plan for the care or supervision of the son/daughter after their death, and also deal with the financial implications of continued dependency (Turnbull, Summers, & Brotherson, 1986). Most families who have a child with a disability are less likely to have been upwardly mobile because the parents have focussed on providing care for the child, rather than advancing their careers (Slater & Wikler, 1986). In addition, because providing care for an adult son/daughter with a developmental delay within the home is a relatively recent trend, parents have few role models to follow (Slater & Wikler, 1986). As noted previously, these dilemmas are potentially very stressful, although there is a lot of inter-family variation (Schilling, Gilchrist, & Schinke,
1984). For example, in contrast to the findings described above, Seltzer and Krauss (1989) reported that mothers providing care to their adult sons/daughters with developmental delays experience less stress than caregivers of the elderly, or same age peers. In fact, mothers with adult off-spring were more satisfied with their lives and healthier than the two comparison groups. Nonetheless, one of the ways to reduce stress (of any degree) is through the activation and utilization of resources. Therefore we need to examine, within the context of research on stress, the way in which resources have been conceptualized.

**Models of Stress**

Although the notion of stress has been widely used, it has generally been poorly defined and conceptualized. In particular, researchers have had difficulty distinguishing between the triggering event(s), namely the stressor(s), and the resultant emotion of stress. According to Lazarus and Folkman (1984), the two are often defined in a circular manner. However, in an attempt to define the construct more clearly, numerous theoretical models or "nomological nets" (Cronbach & Meehl, 1955) have been proposed. Historically, most of these models utilized an individualistic and physiological approach to examining stress, the most notable being Hans Selye’s General Adaptation Syndrome (Lazarus & Folkman, 1984). However, more recently most researchers have adopted a broader, systems type approach to examining
stress, and have explored the concept of stress from a familial and societal perspective. Of these systems models, two familial models have been particularly influential, and are especially significant in this study because they highlight the importance of resources in moderating a family's reaction to a stressor. Specifically, these are Hill's (1958) ABCX model of stress and the Double ABCX model proposed by McCubbin and Patterson (1983). Both models, in order to allow for the possibility of variability in response to the stressor, emphasize the importance of being able to actively, and effectively process information, thus enabling the family to modulate or control its reactions to the stressor (McCubbin, 1979). However, the models differ with regard to their specific application and complexity.

Hill (1949) is generally acknowledged as being the first to propose a comprehensive model of stress. Working from the assumption that separation from someone you love is generally stressful, he examined the experiences of families of servicemen who were separated from their loved ones during the Second World War. From his observations he noted that most families experienced a roller-coaster pattern of adjustment, consisting of an initial stage of disorganization, followed by a period of recovery and re-organization. More importantly, he also identified four components, including two mediating factors, that were especially important in determining the family's reaction to
the stressor (Hill, 1958). These consisted of the nature of the stressor (A), the resources (B) available to the family (including the internal psychological variables of individual family members, intra-familial variables, and extra-familial factors), and the family's perception of the stressor (C). These variables, depending on the family's coping skills (a family's strategies, patterns, and behaviours that are designed to maintain and or strengthen family organization) may or may not result in the family experiencing a crisis (X; defined as the inability of the family to maintain stability within the family system).

Hill's (1958) model became known as the ABCX model of stress. Within this framework a family's resources (Factor B) and perception of the stressor (Factor C) were seen as buffers or mediating variables that could potentially modulate the family's reaction to a stressful event. Figure 1 illustrates a schematic diagram of Hill's model. Like present day theorists, such as McCubbin and McCubbin (1987), Hill (1958) defined stress as resulting from a demand-capability imbalance in which Factors B and C did not enable the family to diffuse, and may have even exaggerated, the harmful effects of the stressor. It should be noted, however, that experiencing stress does not necessarily indicate that the family will experience a crisis. While all families are likely to experience a demand-capability imbalance at some point in their development it does not
Figure 1. Hill's (1958) ABCX model of stress. Adapted from McCubbin & McCubbin (1987).
necessarily prevent the family from maintaining stability within the family system (McCubbin & McCubbin, 1987).

Although Hill's (1958) model represented a turning point in stress research, it's practical application to families with a member who is handicapped is limited because from Hill's perspective the stressor is conceptualized as an acute, discrete event. In contrast, these families often experience chronic on-going stressors (e.g. they have to provide continuing support and care for the disabled family member). In 1983, McCubbin and Patterson proposed the Double ABCX model of stress. This model highlights a family's initial adjustment and, more importantly, their long-term adaptation to a stressor. The model is based on Hill's (1958) paradigm, however, as noted by Wikler (1986a), McCubbin and Patterson added post-crisis variables to the original model so as to operationalize the processes involved in a family's long-term reaction to the stressor. These included the accumulation of life stressors, the processes during the initial phase of adjustment to the stressor, and the range of outcomes associated with family efforts to adapt to the stressor (McCubbin & McCubbin, 1987; see also Orr, Cameron, & Day, 1991). In sum, this model suggests that a family's adaptation to a chronic stressor, such as the presence of a family member with a handicap, represents the combined effects of demands on the family, family resources and strengths (characteristics of the
family that provide them with the potential to meet the
demands being placed on them), family typology (depending on
the relative strengths of a family, it can be one of five
types, namely, balanced, resilient, regenerative, rhythmic
or traditionalistic), a family’s perception of the
situation, a family’s world view and available family
support, all combined with the family’s coping skills
(McCubbin & McCubbin, 1987).

Recently, Orr et al. (1991) employed a path analysis to
evaluate the Double ABCX model. The results essentially
validated the model as effectively conceptualizing long-term
reactions to stressors among families with a member who was
mentally retarded. However, while McCubbin and Patterson
(1983) did not define a specific relationship between the
mediating variables, Orr et al. (1991) note that a family’s
use of resources is influenced primarily by the manner in
which they perceive the stressor. Thus, before resources
are activated by the family, they must form a specific
percept of the stressor as being stressful. Similarly, on a
more individualistic level Lazarus and Folkman (1984) have
also emphasized the important role that cognitions play in
determining an individual’s reaction to a potential
stressor.

Regardless, from my perspective, the most pragmatic
model is the more simplistic conceptualization provided by
Hill (1958). As such, the McCubbin model (McCubbin &
Patterson, 1983) delineates so many potentially moderating variables that it obscures the important role of resources and perceptions in determining the nature of a family's reaction to a stressful event. Indeed in practice, most people use the Hill model, nested in the McCubbin framework, to guide their analyses (Orr, personal communication, 1994).

**Applications of the ABCX/Double ABCX Model**

In the past, a number of researchers have adopted the ABCX/Double ABCX model when examining stress among caregivers with off-spring who were developmentally delayed. For example, Orr, Cameron, Dobson, and Day (1993) investigated the changes in stress associated with caring for children, between the average ages of four and fourteen, who had developmental delays. Similarly, Cameron and Orr (1989) examined stress among a cross-section of families with children of school-age with mental retardation. Byrne and Cunningham (1985), and Konstantareas and Homatidis (1991) provide cogent reviews of the literature. In particular, Byrne and Cunningham (1985) note that until recently most researchers took a "pathological" approach to examining family functioning among families with a member who was mentally retarded.

Indeed, to date, according to Wikler (1986a), most of the studies in this area have investigated the relationship between Factors A (stressor) and X (crisis and/or adjustment) of the Hill (1958) model. Nevertheless, some
studies have focussed on the influence of the moderating
variables, namely the effect of perceptions and resources on
adjustment to stressors. However, of these studies most
have examined perceptions and coping skills. Very little
research has been conducted on the use of resources by
families with children who have developmental delays.
Furthermore, as noted previously, the use of resources by
parents of adult off-spring with developmental delays has
been almost completely overlooked in the literature. This
probably reflects the superordinate role that perceptions
play in determining a family's use of resources. Another
plausible explanation is that the researchers themselves are
often affiliated with professions that are considered to
form part of the resources available to this population, and
as a result tend to overlook their own roles.

Nonetheless, the impact of resources on a family's
ability to provide care for their adult son/daughter with a
handicap obviously warrants further investigation. Hobfoll
and Spielberger (1992, p. 99) comment, "In particular,
resources of the family and how these resources can best be
assessed [need to] receive attention as one of the most
promising areas of family stress research." Knowledge about
the use of resources by parents of adult sons/daughters with
developmental delays is especially important for the
advancement of successful intervention programs targeted
toward this population. Only after resource use has been
examined can appropriate services be implemented to supplement or enhance existing resources (both internal and external).

Examining Resources

Typically, resources have been defined as providing the family with the ability, in light of a potential stressor, to prevent a crisis and facilitate coping (McCubbin & Patterson, 1983). In general, three types of resources have been identified; personal resources, family system resources, and community resources (McCubbin & Thompson, 1987). Personal resources are those characteristics that the individual family members bring to a situation (e.g. a specific attribute such as high self esteem). In particular, McCubbin, Comeau, and Harkins (1980) note that an individual’s education level can especially influence the perception and use of resources. Family system resources are traits of the family as a whole that influence it’s adaptation to a stressor. Hobfoll and Spielberger (1992) identify five factors that have been particularly influential, namely, a family’s flexibility and adaptability, a family’s cohesion, a family’s communication, the clarity of a family’s boundaries, and finally, a family’s sense of mastery and esteem. In addition, a family’s financial status has also been considered a family system resource (McCubbin & Patterson, 1983). Lastly, according to McCubbin and Thompson (1987), community
resources consist of social supports (for example, the utilization of specific organizations in the community) and social networks (meaningful contacts with others, such as friends and relatives). As noted earlier, resources can either be internal psychological variables, or represent external influences.

Furthermore, Hobfoll (as noted in Hobfoll & Spielberger, 1992) has advanced a theory, the Conservation of Resources Theory, in which he postulates that families aim to maximize resource gain and minimize resource loss. Thus, families not only seek out new resources, but also adapt existing resources to meet changing demands. Moreover, Hobfoll believes that resource loss, such as a deterioration in health, or a decrease in income or social supports, and especially the effect of cumulative losses, can be very stressful. While Hobfoll’s work serves to further emphasize the importance of resources, his ideas need to be validated further.

Primarily because resources have been neglected in the literature, only a handful of instruments (usually self-report questionnaires) have been developed to provide researchers with a measure of a family’s resource use. Of these, the Family Environment Scale (FES) developed by Moos and Moos (1983), the Family Inventory of Resources for Management (FIRM; McCubbin et al., 1980) and the Family Crisis-Oriented Personal Evaluation Scale (F-COPES; McCubbin
& Thompson, 1987) are the most popular. Although F-COPES (McCubbin & Thompson, 1987) can be used to measure the availability of external resources, it is most often used to provide researchers with an indication of the problem solving abilities and coping behaviours of the family (Minnes, 1988). In contrast, the FIRM (McCubbin et al., 1980) and the FES (Moos & Moos, 1983) are used, primarily, to provide researchers with a measure of internal and external resource use. Specifically, these measures emphasize internal family resources, personal resources, and community resources.

However, only portions of the FES (Moos & Moos, 1983) pertain to resource use. For example, Wallander, Varni, Babani, Banis, and Wilcox (1989) used only 45 of the test items (approximately 50% of the test) when measuring a family’s resources. However, the psychometric properties of this subtest are not well known, and so a researcher is well advised to use the FIRM instead. Unfortunately though, these shortcomings are also reflected in the FIRM. While it is more suited to measuring resources in general, it too lacks extensive psychometric investigation. Moreover, the normative data associated with the FIRM is also limited. **Psychometrics and the FIRM**

The psychometric properties of a test are generally reported in terms of reliability and validity. Reliability, the opposite of random error (Morf, personal communication,
1993), refers to a test's ability to measure something consistently (Anastasi, 1988). Typically, this is determined by examining test-retest reliability (consistent measurement over time) and/or internal reliability (consistent measurement within the test itself) and reporting a reliability coefficient. For example, the authors of the FIRM (McCubbin et al., 1980) report the internal reliability of the test, although the validity of the test has not been rigorously determined.

In contrast to the technical nature of reliability, the concept of validity is more theoretical (although without reliability a test cannot be valid [Morf, personal communication, 1993]). In the past, validity has been defined as "what a test measures and how well it does so" (Anastasi, 1988, p. 139). That is, it refers to what can be inferred from test scores (Anastasi, 1988). In the past, numerous forms of validity have been identified. For example, Kazdin (1992) identifies at least six distinct types of validity, including convergent and discriminant validity (the similarity or dissimilarity between scores on the said test and other tests designed to measure the same or dissimilar constructs) and external validity (the ability to generalize from specific test results to other situations).

In contrast, Anastasi (1988) categorizes these six types of validity into three groups. These include
criterion validity (also termed "practical validity" by Campbell in 1960 and involves examining the test's ability to predict performance in test-related activities), content validity (examining the content of test items to see if they reflect the construct being measured) and construct validity. The criterion and content validities of a test stand alone in separate categories whereas construct validity is conceptualized as including information regarding a test's convergent, discriminant, and external validities (Anastasi, 1988).

As such, Cronbach and Meehl (1955) were the first to specifically conceptualize and define construct validity. Specifically, it refers to "the [underlying] postulated attribute or quality that is assumed to be reflected in test performance" (Cronbach & Meehl, 1955, p. 283). Since its conception, many have argued that construct validity is the most powerful category of validity associated with a test. For example, Messick (1980; cited in Anastasi, 1988) believes that the term validity should be applied solely to the determination of a test's underlying construct. This reflects a common belief that construct validity encompasses not only other forms of validity but also other categories.

However, as Anastasi (1988) notes, determining the construct validity of a test requires the gradual accumulation of data from various sources, including evidence regarding the test's content and criterion
validities. Certainly, test consumers must be wary of simply accepting the name of a test as evidence of what a test measures. As noted by Campbell (1960), test constructors are prone to re-ify constructs through their choice of test names or scales.

As noted previously, the authors of the FIRM (McCubbin et al., 1980) present data regarding the internal reliability of the test, however, information about the validity of the test is limited. In particular, the content validity of the test is not specifically addressed. Moreover, a review of the existing literature, including the most recent Mental Measurements Yearbook (Kramer & Conoley, 1992), resulted in the present author finding only one study that examined the validity of the FIRM, and even that was done in a circuitous manner. The study, conducted by Halvorsen (1991), investigated the convergent validity of the Family Stress and Support Inventory (FSSI), a test Halvorsen developed, with the FIRM (McCubbin et al., 1980) and the Family Inventory of Life Events and Changes (FILE), which was also developed by the McCubbin research group (McCubbin, Patterson, & Wilson, 1981).

Gathering more information about the validity or scope of the FIRM (McCubbin et al., 1980) is especially important, because despite being developed from data on families that had a child with either myelomeningocele (defined by Melloni in 1985 as an abnormal gap in the vertebral column through
which membranes and nerve roots protrude - spina bifida) or cerebral palsy (McCubbin et al., 1980), it is often used to measure resources in other dissimilar populations. For example, Phipps and Drotar (1990) utilized the FIRM to provide a measure of resource use in parents whose children were prone to apnea. In sum, despite the continuing use of the FIRM (McCubbin et al., 1980) in research (Gillis, Neuhaus, & Hauck, 1990; Phipps & Drotar, 1990) few if any independent researchers have critically examined it's validity and overall generalizability.

**Rationale and Purpose of Present Study**

The purpose of the present study is two-fold. While the general aim is to examine the use of resources in caregivers of adult off-spring who are developmentally delayed, we also want to address the lack of psychometric data, more specifically the lack of content validity, associated with the FIRM (McCubbin et al., 1980). As such, examining the content validity of the test will also provide researchers with indirect evidence of it's construct validity.

Overall, this will be achieved via analysis of transcripts from interviews that were conducted with mothers of adult developmentally delayed children as part of a prior study (see method section for further information). To date, these interviews have not been examined in detail. Specifically, a qualitative approach will be employed to
identify the resources used by the aforementioned mothers. Once these have been delineated, they will then be compared, quantitatively, to the type of resources specifically measured by the FIRM, as defined in the test manual (McCubbin et al., 1980), and by mothers' scores on the test. It is anticipated that from this analysis we will be able to determine if the FIRM (McCubbin et al., 1980) accurately reflects the types of resources employed by families of adult off-spring with developmental delays, and hence provide evidence about the generalizability of the test to members of this population. Furthermore, the qualitative data will also be used to determine if resource use amongst members of this population varies according to the age of the mothers.

Similarly, capitalizing on additional information, also collected around the time of the interviews and incorporated in previous studies (see methods section), we will also explore the corollary relationship between the qualitative data and quantitative measures of mothers' present levels of stress, the intensity of a potential stressor (namely the adult off-springs' behaviour problems) and mothers' coping behaviours. To date, this comparison between qualitative data and these types of test scores has not been conducted with members of this population.

In the past, most researchers have adopted a quantitative approach to such data analysis. However, using
a triangulation approach, which combines the use of qualitative and quantitative data, Leavitt (1990) was able to provide evidence about the convergent validity of numerous tests in her study. As noted by Miles and Huberman (1984, p. 15) qualitative data "are a source of...rich descriptions and explanations...." Unquestionably, using the subjects' own words to convey meaning provides the researcher with a deeper understanding of their experiences than would be elicited from just an analysis of a summary numeral obtained through administering and scoring a test. In fact, Le Compte and Goetz (1982; cited in Adams, 1982), conclude that the validity achieved through the data collection and analysis of qualitative work is the major strength of such an analysis.

In conclusion, this study will take a qualitative approach to examining the use of resources among mothers of adult sons/daughters who are developmentally delayed. As noted previously, the use of resources plays an important role in the moderation of stress experienced by mothers providing long-term care to their children. It is only by examining the use of such resources that effective intervention programs can be designed to further facilitate resource use. Initially, the three general resource categories discussed earlier, namely personal, family, and community (psychological and sociological factors) will be used to guide the analysis.
CHAPTER II
METHODOLOGY

Participants

The participants consisted of 28 mothers from Southwestern Ontario who, at the time of their interviews, had an adult son/daughter with a developmental delay residing with them at home. Based on exclusionary criteria, which consisted of eliminating mothers who did not have a son/daughter with a developmental delay residing at home and secondly, exclusion of mothers whose interviews were incomplete, that is, interviews in which relevant demographic information was missing, the participants were selected from a group of 39 mothers. All the mothers had originally completed the interview as part of a larger exploratory study examining stress, resources, and coping in mothers of adult off-spring with developmental delays (Cameron, Armstrong-Stassen, Orr, & Loukas, 1991a; see also Cameron, Orr, & Loukas, 1991b). As such, they were recruited through community organizations that provided services to this population.

At the time of their interviews, the age of the participants selected for inclusion in the final sample ranged from 47 to 79 years ($N = 28$, $M = 61.11$, $SD = 8.38$). All participants were Caucasian and approximately 60.7% were married. The remaining subjects were either divorced (7.1%), widowed (28.6%), or living in a common law
relationship with their partners (3.6%). In addition, Table 1 illustrates the education and socioeconomic levels (as determined by Hollingshead’s four-factor index of social status [Hollingshead, 1975]) of participants. Clearly, the two highest categories of socioeconomic status, medium business, minor professional, and major business and professional were under-represented in this sample. Similarly, less than 50% of the sample reported attaining an education level of Grade 12 or higher. However, with respect to education level, this skewed sample is in fact representative of the actual population in this area (Statistics Canada, 1994).

Finally, the participants’ off-spring, 57.1% of whom were male, ranged in age from 22 to 53 years (N = 28, M = 32.14, SD = 8.44). Almost all of them (89.3%) attended sheltered workshops during the day, however, 10.7% either worked elsewhere, attended a day program, or stayed at home. See Appendix A for a description of the primary diagnoses associated with these children.

Materials

Interviews. Semi-structured interviews were used to elicit relevant information from participants. Moreover, so as to ensure that the interviews would be comparable, an interview guide, containing a thematic outline, was followed. This guide, which is summarized in Appendix B, included topics such as the participant’s reaction to the
Table 1.
The Socioeconomic Status and Education Levels Represented in the Sample (N = 28)

<table>
<thead>
<tr>
<th>Demographic Characteristics</th>
<th>n</th>
<th>% of Sample</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Socioeconomic Status</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Major Business and Professional</td>
<td>3</td>
<td>10.7%</td>
</tr>
<tr>
<td>Medium Business, Minor Professional</td>
<td>2</td>
<td>7.1%</td>
</tr>
<tr>
<td>Skilled Craft, Clerical Sales</td>
<td>9</td>
<td>32.1%</td>
</tr>
<tr>
<td>Semi-skilled, Machine Operator</td>
<td>9</td>
<td>32.1%</td>
</tr>
<tr>
<td>Unskilled</td>
<td>5</td>
<td>17.9%</td>
</tr>
<tr>
<td><strong>Education Level</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Completed University</td>
<td>1</td>
<td>3.6%</td>
</tr>
<tr>
<td>Completed College</td>
<td>6</td>
<td>21.4%</td>
</tr>
<tr>
<td>Some College</td>
<td>1</td>
<td>3.6%</td>
</tr>
<tr>
<td>Grade 13</td>
<td>2</td>
<td>7.1%</td>
</tr>
<tr>
<td>Grade 12</td>
<td>1</td>
<td>3.6%</td>
</tr>
<tr>
<td>Grade 9-11</td>
<td>8</td>
<td>28.6%</td>
</tr>
<tr>
<td>Grade 8 and below</td>
<td>9</td>
<td>32.1%</td>
</tr>
</tbody>
</table>
realization that their child was handicapped, their concerns about the future, their utilization of various support networks, and their attitudes regarding their child's personality. In general, however, the interviewer (the same interviewer conducted all the interviews) was mindful to follow the participant's lead, interrupting only to clarify or reflect upon the nature of the conversation. Indeed, it should be noted that most of the information about mothers' resource use was derived from open-ended questions.

Overall, the interviewer presented herself as a respectful, friendly individual who was genuinely interested in learning about the participants' experiences. The interviews were unhurried, lacking specific time constraints (other than those imposed by the participants) or deadlines; most of the interviews took at least two to three hours to complete.

Following informed consent, the interviewer, a former public health nurse (female) travelled to the participant's home to conduct the interview. This promoted a feeling of familiarity among participants, which served to reduce their anxiety about disclosing personal information to a stranger, and encouraged them to talk freely. Similarly, the confidential nature of the interview was also emphasized so as to encourage free speech. Unless the participant requested that the tape recorder be turned off momentarily, the entire interview was recorded on tape. The interviews were then transcribed verbatim for later analysis - the
information was transformed into type written transcripts that, on average, were approximately 40 pages in length. If, during the interview, the participant became distressed the interviewer stayed at the end of the interview to counsel the participant.

Following the interview, the interviewer also recorded her own reactions (and other observations) to the interview, for example, commenting on the validity of the statements made by the participant. These comments were included at the end of each transcript and were read as part of the analysis.

As noted elsewhere, the measures described below formed part of the original test battery administered to mothers by Cameron et al. (1991a, 1991b) around the time of their interviews.

The Family Inventory of Resources for Management (FIRM). The FIRM, developed by McCubbin et al. (1980), is a self report inventory designed to assess the availability of resources (internal and external) to the family. It consists of 68 items which respondents rate on a four point likert scale, ranging from 0 to 3, depending on how well the item describes the family. Zero indicates that the item does not describe the family and three indicates that the item describes the family almost perfectly. Scored using templates, high scores on the test indicate that the family
has a wide range of resources available to them. Low scores indicate that the family has a limited number of resources that they can utilize.

Constructed in a rational (not empirical) manner it is based on data collected from 322 families with children who had spina bifida or cerebral palsy, and includes measures very similar to those identified by Hobfoll and Spielberger (1992) in the introduction. As such, McCubbin et al. (1980) factor analyzed the aforementioned data, and then used the resultant factors to guide the construction of subscales in the FIRM. Specifically, the FIRM is comprised of six subscales. Of these, four (Family Strengths I, Family Strengths II, Extended Family Social Support, and Financial Well-Being) reflect dimensions that emerged from the factor analysis (see Table 2 for a detailed description of each scale). The two remaining subscales provide researchers with measures of potentially confounding variables, namely, financial support and social desirability. However, when calculating an overall measure of resource availability these scales are disregarded, and the researcher adds the scores from the first four subscales. As noted above, results can be reported in terms of a universal resource score, or as individual subscale scores.

McCubbin and Comeau (1991) report that the overall internal reliability of the four primary subscales is .89; individual subscales range from .62 (Extended Family Social
### Table 2.

**A Description of the Main Subscales in the FIRM**

<table>
<thead>
<tr>
<th>Subscale</th>
<th>Test Items</th>
<th>Areas Covered</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family Strengths I (FSI): Esteem and Communication</td>
<td>15</td>
<td>Family Esteem, Communication</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Mutual Assistance, Optimism, Problem Solving, Autonomy</td>
</tr>
<tr>
<td>Family Strengths II (FSII): Mastery and Health</td>
<td>20</td>
<td>Mastery, Family Mutuality, Physical &amp; Emotional Health</td>
</tr>
<tr>
<td>Extended Family Social Support (EXTFSS)</td>
<td>4</td>
<td>Help &amp; Support from Relatives</td>
</tr>
<tr>
<td>Financial Well-Being (FINWB)</td>
<td>16</td>
<td>Ability to Meet Financial Commitments, Adequacy of Reserves, Helping Others, Optimism about Future</td>
</tr>
</tbody>
</table>
Support) to .85 (Family Strengths I, Family Strengths II, Mastery & Health, Financial Well-Being). Similarly, the intercorrelation between the four subscales ranges from .19 (Financial Well-Being and Extended Family Social Support) to .37 (Extended Family Social Support and Family Strengths I).

The validity of the FIRM has only been investigated in a limited manner. As noted elsewhere, the FIRM has been moderately correlated with selected scales from the Family Environment Scale (FES; Moos & Moos, 1983). For example, McCubbin and Comeau (1991) state that the correlation between Family Strengths II and the Cohesion subscale of the FES is .41. In addition, the discriminant validity ($r = .10$) of the FIRM and the Family Stress and Social Support Inventory (FSSI; Halvorsen, 1991) has also been established.

**Behaviour Problems.** This measure was created by Cameron et al. (1991a, 1991b) to provide researchers with an indication of the extent to which mothers' off-spring engaged in problematic, potentially stressful, behaviours. In otherwords, it is a measure of a potential stressor. Cameron et al. (1991a, 1991b) constructed this variable from information, regarding problem behaviours, collected on a demographic questionnaire given to mothers as part of the original assessment battery. The potential problem behaviours were namely, harming others, harming self,
destroying property, interrupting the sleep of others, eating in an irritating manner, irritating others, wandering away from the home, sexual aggressiveness, and "other" problem behaviours. Mothers rated these behaviours as occurring either frequently or occasionally. Total scores ranged from 0 (all problem behaviours occur occasionally) to 9 (all problem behaviours occur frequently).

**Family Crisis Oriented Personal Evaluation Scales (F-COPES).** F-COPES, developed by McCubbin, Olson, and Larsen, (1987) was used to provide a measure of mothers’ coping behaviours. This test is a self-report inventory designed (in a rational manner), primarily, to provide a measure of a family’s problem solving attitudes and coping behaviours (Cameron et al., 1991a). It is comprised of 30 items which the respondent rates on a five point likert scale ranging from strongly disagree (1) to strongly agree (5).

Furthermore, according to McCubbin et al. (1987) 29 of these 30 items constitute 5 subscales, namely, Acquiring Social Support (9 items designed to measure the family’s ability to procure help from friends, neighbours and relatives), Reframing (8 items which measure the family’s ability to change stressful events into something that they can deal with), Seeking Spiritual Support (4 items), Mobilizing Family to Acquire and Accept Help (4 items which assess the family’s ability to actively pursue and accept help from external sources), and Passive Appraisal (4 items which
measure the degree to which families accept stressful events).

Like the FIRM, results can be reported in terms of each subscale, or summed across subscales to provide an overall score. Scores are keyed in the positive direction, so that a high score indicates that the family has a wide repertoire of problem solving behaviours. A low score signifies that the family has limited access to problem solving behaviours.

Over a one month period the test-retest reliability of the test is .81. Overall internal reliability for the F-COPES is .77. Similarly, the internal reliability of each subscale is as follows: Acquiring Social Support .83, Reframing .82, Seeking Spiritual Support .80, Mobilizing Family to Acquire and Accept Help .71, Passive Appraisal .63. In contrast, the authors of the test do not specifically present validity data (McCubbin et al., 1987).

**Short-Form Questionnaire on Resources and Stress (QRS-SF).** In order to determine the mothers' present levels of stress, we used scores from the Patient Problems domain of the QRS-SF. The QRS-SF was devised by Holroyd (1987), in a rational manner, to measure the effects of a child's handicap on the mother. However, the Patient Problems domain has been used to provide a measure of mothers' present levels of stress (see Cameron et al., 1991b).

As noted by Cameron et al. (1991b), the QRS-SF is a self-report questionnaire that consists of 66 true/false
items. According to Holroyd (1987) these items were derived from a factor analysis of the entire QRS (285 items) and are divided equally among 11 subscales (namely, Dependency and Management, Cognitive Impairment, Limits on Family Opportunities, Life Span Care, Family Disharmony, Lack of Personal Reward, Terminal Illness Stress, Physical Limitations, Financial Stress, Preference for Institutional Care, and Personal Burden for Respondent). These subscales can then be further merged to produce three general areas or domains. The first, mentioned above, consists of Patient Problems, the second focusses on Respondent Attitudes, and the third emphasizes Family Problems. Of interest to us is the area of Patient Problems, which is composed of the following subscales: Dependency and Management, Cognitive Impairment, and lastly Physical Limitations. Scored using templates provided by the author, the greater the level of stress, the higher the score on the subscales, and subsequently also the domains. Similarly, low scores symbolize low levels of stress.

Psychometric data for the QRS-SF is limited, however, Holroyd (1987) reports that the overall internal reliability is .85 (N = 528). The internal reliability of the various subscales ranges from .23 (Lack of Personal Reward) to .80 (Cognitive Impairment). More specifically, the internal reliabilities of the subscales Dependency and Management, and Physical Limitations, that along with Cognitive
Impairment comprise the area of Patient Problems, are .72 and .65 respectively (Holroyd, 1987). Holroyd (1987) presents some evidence for the criterion validity of the QRS-SF, but notes that more studies need to be conducted.

Procedure/Analysis of Qualitative Data

To reduce the interviews to a form that was more amenable to processing the interviews were analyzed in three stages.

The first stage of data reduction involved segmenting (see Appendix C for segmenting rules provided by Hakim-Larson, personal communication, 1995) the interviews into meaningful components. As suggested by Taylor and Bogdan (1984) the interviews were read twice and then, following the prescribed rules, broken into segments.

The next two stages followed an analytic-inductive approach to data analysis. As such, the interviews were used to generate theoretical categories (that is, the framework for the analysis was derived directly from the data) rather than applying existing categories to the data in an attempt to verify or nullify them, a process termed deductive analysis (Lincoln & Guba, 1985). Although the aim of the study was not to use the data to develop a specific theory, which would be indicative of taking a theoretically grounded approach to data analysis (pioneered by Glaser & Strauss, 1967), a technique formally developed under the auspices of grounded theory, namely the "constant
comparative" method of data analysis was employed to formally code and analyze the interviews. See Lincoln and Guba (1985) for an extensive discussion of this technique.

First, using the aforementioned definition of participants' resources as those factors, psychological and social, which have enhanced their ability to provide long-term care to their adult off-spring, we identified every interview segment (regardless of whether the type of resource being described had previously been noted) in which the participants discussed or illustrated (behaviourally) resources. Analyzing the interviews thematically, the segments were coded in terms of the major topics or themes present in each. While some authors (see Miles & Huberman, 1984) suggest using an a priori coding scheme, the codes used in this analysis were generated from the data themselves, and refined as the analysis continued (thus ensuring that the richness of the data remained intact). At this stage of the procedure, the codes were fairly general and descriptive in nature, because the aim was to delineate only segments that dealt with resources: in the past, this type of coding has been referred to as "open coding" (Strauss & Corbin, 1990).

Following standard practice, the codes were recorded in the margin on the left of the interview transcript. This is distinct from other ideas or reflective observations that were recorded as "memos" in the margin on the right hand-
side of the interview transcript (Miles & Huberman, 1984). Each interview was analyzed individually, with the investigator constantly comparing coded categories between interviews so as to ensure that the categories identified were as homogenous and consistent as possible (hence the term "constant comparison" approach).

Subsequent to the conclusion of Stage 2, the identified resource segments were studied in more detail. The aim of this last stage was to specifically delineate the various component parts that make up the more general or superordinate resource construct (a process identified as "axial sorting" by Strauss and Corbin [1990]). A procedure similar to the one described above was executed. First, all the pertinent segments from every interview were read twice. They were then transcribed onto index cards (a code at the top of each index card identified the page and interview from which each segment was derived). Next, each index card was sorted into one of a number of groups, each of which contained cards that reflected the same, or related content. While some of the categorizing was done on a descriptive basis, we also assigned cards on an inferential basis, following consideration of the latent content. Adhering to the constant comparative paradigm, each card was compared to preceding cards during the categorizing process. In other words, the content of a card that was placed in one group was compared to other cards in that group and also
cards in the other groups. New categories were formed when a card did not seem comparable to cards in any of the other categories. When the content of the card was judged to be unassignable then it was discarded. However, as Lincoln and Guba (1985) note, no more than 5 to 7 per cent of cards should be discarded. If more than 5 to 7 per cent of the cards are discarded it is typically indicative of an inadequacy in the category set.

When all the cards were processed in this manner the groups or categories that had been formed were reviewed. At this time, we generated labels for each category. That is, by reassessing the cards in each category we could ensure that there was no overlap between the categories. More importantly, the rules for card placement in the groups became explicit, thereby allowing the categories to be characterized descriptively. As such, these categories represent the various component factors that form the superordinate resource construct, generated from these interviews.

Initially, the processes of segmentation, identifying resource segments, and categorization, described above, were conducted on the discarded interviews (N = 11). This pilot study enabled the author to practise her coding skills and also helped her develop a sense of the information obtained in the interviews.

In addition, at the end of each stage, before
proceeding to the next, the reliability of the results was determined. In the pilot study, following guidelines from Miles and Huberman (1984), an independent male rater analyzed ten random pages from each of the discarded interviews (the rater was male so as to guard against any gender bias on the part of the investigator). The two raters then compared their segmenting, coding, and categorization schemes, and resolved any differences.

In an effort to look at the objectivity of the analytic process an additional (female) independent rater was utilized during the formal study. This was to control for possible coercion of the first rater by the investigator, which could potentially inflate the reliability scores. As such, in the formal analysis, the first rater analyzed five pages from each interview, while the second rater analyzed two pages from each of the five pages assigned to the first rater. Reliabilities were calculated, at each stage, between the investigator and the first rater, and also between the first and second independent raters.
CHAPTER III
RESULTS

Overview of the Analysis

The formal analysis (N = 28) was preceded by a pilot study (N = 11) designed to refine the qualitative techniques that we employed. As noted previously, each study followed a three stage procedure. Stage 1 involved segmenting the interviews into meaningful components. Stage 2 consisted of identification of those segments that pertained to resource use. Finally, in Stage 3 we grouped the resource segments, identified in Stage 2, into categories.

The categories that emerged from the formal analysis were then compared, using correlational methods, to mothers' scores on the FIRM, Behaviour Problems, F-COPES, and the Patient Problems domain of the QRS-SF. Finally, a multivariate analysis of variance (MANOVA) was conducted to determine whether mothers' patterns of resource use, identified via the interviews, were related to their age.

Reliability

In the pilot study (N = 11), the inter-rater reliabilities between the investigator and the first independent rater were .80 (n = 692) for Stage 1, and .93 (n = 692) for Stage 2. The reliability (or kappa coefficient) for Stage 3 of the pilot study was .86 (n = 75) before correction for chance agreement between the observers, and .82 (n = 75) after the correction. However, because we were
still refining the technique at this time it is likely that these reliability coefficients are underestimations of the potential inter-rater reliability.

In the formal analysis (N = 28) the reliabilities of the observations made by the investigator and the first independent rater were .91 (n = 846) in Stage 1, .94 (n = 846) in Stage 2, and a kappa coefficient of .95 (n = 101) in Stage 3.

In an effort to look at the objectivity of the analytic process I trained a second independent rater who subsequently analyzed a portion of the data from the formal analysis. The reliability of observations between the first and second independent raters were .82 (n = 352), and .95 (n = 352) for Stages 1 and 2 respectively. The kappa coefficient (chance-corrected reliability) for Stage 3 was .94 (n = 37).

As such, the reliability of each stage was calculated via the number of inter-rater agreements divided by the number of inter-rater agreements plus disagreements, and where relevant (Stage 3) corrected for chance agreement between the raters. Before correction for chance agreement between the raters, the reliability coefficients should ideally be no less than .85, and absolutely no less than .70 (Miles & Huberman, 1984). Similarly, following guidelines provided by Landis and Koch (1977; cited in Everitt & Hay, 1992) the chance-corrected reliabilities (kappa
coefficients) should not fall below .21. In the present study all the reliability measures exceeded minimum expectancies.

**Categorization**

In total, 326 resource segments (N = 28, M = 11.5, SD = 4.5) were identified during the formal analysis, however, four (1.2%) segments were discarded during the categorization process because they were inappropriate. Overall, ten categories of resources namely, Community Agencies (CA), Employers (EY), Family Members (FY), Friends/Neighbours (FD), Health Professionals (HP), Husbands (HB), Informal Networks (IN; contact with other mothers who also had adult off-spring with developmental disabilities), Personal Resources (PR; specific personality attributes that were identified as being helpful to the mothers), Religious Faith (RF), and Schools (SC) emerged from the categorization process as being especially helpful to the mothers in caring for their off-spring at home. Examples of each category are summarized in Appendix D.

The number of resource categories employed by each mother ranged from 1 to 7 (N = 28, M = 5.1, SD = 1.7). More specifically, the individual frequency count of each category for every mother is illustrated in Appendix E. The most frequent number of endorsements for any category was eight, while the least was zero. There were no aberrantly high endorsements in any category by one mother, which
indicates that the data were not being unduly influenced by one or two participants. The overall frequency of each category (collapsed across participants) is summarized in Figure 2. As illustrated in Figure 2, Community Agencies were endorsed most often and Employers the least often. Specifically, more than 50% of the resources identified were either Community Agencies (22.0%), Family Members (19.9%), Health Professionals (15.2%), or Personal Resources (12.4%). Next in importance were Friends/Neighbours (8.1%), Husbands (7.1%), Informal Networks (6.8%), and Religious Faith (6.2%). Lastly, 2.2% of the resources belonged to the categories of Schools and Employers.

Although not specifically included in the formal analysis three other types of information emerged from the analysis. Firstly, a number of mothers (N = 19; 68% of the sample) identified three areas in which they felt that the support they were presently receiving was inadequate. For example, mothers (N = 15; 54% of the sample) talked about the need, in general, to increase the availability of services to members of this population. Specifically, one mother said, "..we would like more help for her...we'd have more freedom to go out, if we had more help for her care..." Elaborating on this theme, two other mothers were concerned about their limited access to transportation, stating that they would "definitely" go out more if they had the transportation to do so. Similarly,
Figure 2. The frequency of resource categories identified in the formal analysis.
some of the mothers (N = 8; 29% of the sample) were
discouraged by the lack of adult advocates available to
befriend their adult sons/daughters. One mother explained,
"...I would be so happy if somebody took her out. I would be
happy for her..." In particular, the lack of male advocates
was noted by 19% (N = 3) of the mothers who had male off-
spring. For example, one of the three mothers stated,
"...you see what the problem is, he needs to have more
network[s], especially male network[s] and it's just not
there..."

Furthermore, 32% (N = 9) of the mothers identified the
adult off-spring themselves as a resource. A series of
analyses of variance (ANOVAs), utilizing unweighted means,
revealed that these mothers (N = 9) did not vary
significantly from the remaining sample (N = 19) in their
levels of stress (Patient Problems domain of the QRS-SF),
the intensity of the problem behaviours exhibited by their
off-spring, overall coping behaviours (total scores on the
F-COPES), total resource availability (determined by overall
scores on the FIRM), or total number of resource (identified
via the interview data) that they employed. However, the
average age (N = 9, M = 66.8, SD = 7.7) of this group of
nine mothers was significantly higher than the rest (N = 19,
M = 58.4, SD = 7.4) of the sample (F(1, 26) = 7.51, p <
0.05). It appears that having the adult son/daughter live
with them provides a source of companionship that serves to
off-set the increasing alienation and isolation often associated with old-age. For example, one mother, articulated this by noting that having her daughter living at home "...has been a great reward, especially after my [her] husband died." Similarly, another mother stated, "...she's the greatest blessing we ever had...since my husband passed away she's my best friend."

Finally, having read all the interviews, it appears that present resource use was dictated by past resource use. That is, where possible, mothers (N = 28) presently continue to use resources that were available to them when their adult son/daughter was a child.

**Relationship Between the Qualitative Data and the FIRM**

A correlation between the total number of resources (collapsed across categories) employed by each mother (as identified from the interviews) and their total score on the FIRM revealed that the two were not significantly related \( r = -0.11 \). However, a correlation between the frequency with which mothers endorsed individual resource categories and their scores on the four primary subscales of the FIRM (FSI, FSII, EXTFS, and FINWB) revealed that the Religious Faith category was significantly related to the FSI subscale of the FIRM \( r = 0.38, p < 0.05 \). Higher scores on this subscale are related to a mother's increasing dependence on her religious faith as a resource to help her deal with stress.
Relationship Between the Qualitative Data and Other Variables

**Stressor.** The correlation between the total number of resources endorsed by each mother and a potential stressor, namely the intensity of behaviour problems exhibited by the mothers' off-spring (determined by a mother's response to a demographic questionnaire described in the methods section), was not significant \( r = .25 \). Similarly, a correlation between the frequency of individual resource categories endorsed by mothers and the intensity of behaviour problems exhibited by their adult off-spring revealed that none of the ten resource categories were significantly related to the behaviour problems reported by the mothers.

**Coping Behaviours.** The correlation between the total number of resources identified by each mother and their overall coping behaviours (measured via mothers overall scores on F-COPES) was also not significant \( r = -.12 \). However, closer inspection revealed that the resource category Schools was significantly correlated with the F-COPES subscale Mobilizing Family to Acquire and Accept Help \( r = .45, p < 0.05 \). Similarly, the resource categories Health Professionals and Personal Resources were significantly correlated with the subscales Passive Appraisal \( r = .40, p < 0.05 \) and Reframing \( r = .45, p < 0.05 \), respectively. High scores on these subscales are related to increasing reliance on the resources depicted by
the relevant categories.

**Stress.** The correlation between the overall number of resources identified by each mother and the mothers present levels of stress, as measured by the Patient Problems subscale on the QRS-SF, was not significant ($r = -.06$). However, a more detailed analysis, that employed the frequency with which each mother endorsed individual resource categories, revealed that the category of Friends/Neighbours was significantly correlated with mothers present levels of stress ($r = .40$, $p < 0.05$). This indicates that higher levels of stress are associated with increasing interactions with friends and neighbours.

**Age of Mothers.** The mothers were divided equally into two age groups, 47 - 60 ($N = 14$) and 61 - 79 ($N = 14$) years of age, and resource use was compared. Total resource use by each group was virtually identical. One hundred and sixty-two resources were identified by the younger group, and 164 by the other group. In addition, a multivariate analysis of variance (MANOVA) was conducted to determine whether individual categories of resource use varied by age. This analysis revealed that the pattern of resource use identified from the interviews was not significantly related to age ($\text{Wilk's Lambda} = 0.63$; $F(10, 17) = 1.00$, $p = 0.48$).
CHAPTER IV
DISCUSSION

Reliability

Examination of the inter-rater reliability coefficients reveals that the qualitative procedure/analysis employed in this study is reliable. A practice effect, illustrated via the improvement of inter-rater reliabilities from the pilot study to the formal analysis, was observed for the investigator and the first rater. This provides evidence of the effectiveness of the pilot study in allowing us, by identifying and resolving difficulties with the procedure, to streamline the analysis and circumvent problems that might have otherwise contaminated the formal analysis. In addition, the similarity of the reliability coefficients obtained by the investigator and the first rater, and the first and second raters, provides further evidence of the reliability of the procedure.

Categorization

The ten categories (Community Agencies, Employers, Family Members, Friends/Neighbours, Health Professionals, Husbands, Informal Networks, Personal Resources, Religious Faith, and Schools) that emerged from this study reflect the framework that was used to guide the analysis. Like the McCubbin and Thompson (1987) approach, these ten categories can be merged to form three super-ordinate categories, reflecting personal, familial, and community resources.

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Personal resources would include the personal resource and religious faith categories that emerged from the analysis. Similarly, familial resources would result from the combination of the family members and husband categories. Lastly, community resources would represent the merging of community agencies, employers, friends/neighbours, health professionals, informal networks, and schools categories respectively.

As such, the ten aforementioned categories are similar to those reported by Stanfield (1973) who conducted interviews with American mothers who had adult off-spring with developmental delays living with them. Specifically, Stanfield (1973) reported that community agencies and family members played an important role in helping the mothers to provide care for their children. However, in potential contradiction to our findings, Stanfield (1973) also reported that neighbours played an integral role in helping mothers provide care to their off-spring. Due to the nature of our analyses, which prevent us from determining causality, our finding that high levels of stress are correlated with increased interactions with friends and neighbours can be interpreted in one of two ways. First, it could be that when experiencing high levels of stress, mothers seek out their friends and neighbours, or secondly it is possible that the influence of friends and neighbours creates stress for the mother. The first explanation would
support Stanfield's (1973) findings, whereas the second would counter his results.

Further general support for our findings comes from Jennings (1987) who, in a review article, notes that community agencies, especially those that provide respite care, are invaluable to mothers providing care within the home to adult sons/daughters with developmental delays. Indeed, given the frequency with which community agencies were identified as helpful by mothers in this analysis, and their call for more community support (in-home respite care, transportation, and advocates, especially male advocates) the importance of community resources should not be overlooked. Rather, even in a time of declining government resources such community services need special consideration. However, according to the results obtained here, we must be careful not to overlook the central role that mothers' personal resources, family members, informal networks, and perhaps friends and neighbours can also play in helping, by reducing stress, to provide care for the child who is developmentally delayed.

In contrast to the pathological model of family functioning, in which children with developmental disabilities are viewed as a burden to the family system, the results from this study, like those of Seltzer and Krauss (1989), indicate that adult off-spring with developmental delays can enrich the family environment. In
some instances, especially as mothers get older, the adult off-spring serve as resources to their mothers. This is in contrast to traditional models, which have focussed almost exclusively on the negative aspects of caring for a child who has a handicap (Byrne & Cunningham, 1985). However, as Cameron postulated in 1979, with sufficient resources, it is possible to successfully provide care within the home for adult off-spring with developmental delays.

Many of the resources identified by mothers of adult off-spring are the same as those utilized by mothers with young children who are developmentally disabled. For example, Cameron (1979), highlights the role of informal networks, and health professionals in helping a mother adjust to the birth of a child who is disabled. Similarly, Schilling et al. (1984) also discuss the importance of social supports.

In the past, in order to facilitate later parental adjustment researchers (for example, Drotar et al., 1975) have emphasized the importance of providing new mothers with counselling. Similarly, it would appear that the type of resources employed or developed by mothers at this time dictates later resource use. It is our general impression, that the type of resources presently employed by mothers of adult sons/daughters with developmental delays is determined by the resources they utilized in the past, primarily when their son/daughter was a child. If this is accurate it adds
validation to the Conservation of Resources theory, in which Hobfoll (Hobfoll & Spielberger, 1992) postulates, amongst other things, that families adapt past resources to present demands. Similarly, it provides some support for the suitability of Hill’s ABCX "crisis" model to families who have been exposed to long-term stressors. At a more basic level, it highlights the importance of ensuring that resources (internal and external) are made available, via direct intervention, to mothers within the first few months of their child’s life.

**Relationship Between the Qualitative Data and the FIRM and F-COPES**

Based on the categories that emerged from the qualitative analysis, it would appear that while the FIRM may have some useful aspects (for example, Cameron et al., in 1991b, found that the FSII scale was related to reports of stress from mothers in this population) it failed to tap the types of resources that mothers were describing in their interviews. Only one of the ten categories, Religious Faith, was significantly related to any of the four primary subscales on the FIRM. Specifically, this category (Religious Faith) appears to overlap with the Family Strengths I: Esteem and Communication (FSI) subscale of the FIRM, which measures, esteem, communication, mutual assistance, optimism, problem solving ability and autonomy, amongst family members and external sources. This
relationship probably reflects the fact that mothers who use their religion to help them moderate the effects of stressors are provided with an outlet for their feelings (communication) through prayer, and experience a sense of hopefulness (optimism) that "God" is looking out for them. However, we may also have expected the FSI subscale to correlate with the categories of Personal Resources, Family Members, and Husbands. Similarly, the Family Strengths II: Mastery and Health (FSII) subscale, based on the description provided by the authors (McCubbin et al., 1980) might have been expected to correlate with the categories of Schools, Community Agencies, Health Professionals, Personal Resources, and Husbands. Lastly, we might have predicted that the category of Family Members may have been correlated with the Extended Family Social Support (EXTFSS) subscale.

The surprising finding that there was minimal overlap between the categories from the analysis and the FIRM brings into question the suitability of this test for measuring the type of resources, as we defined them, that emerged from the analysis. In comparison, the categories which we generated appear to be somewhat better suited to F-COPES. Three of our resource categories, Schools, Health Professionals, and Personal Resources, were each related to one of three subscales on F-COPES, namely, Mobilizing Family to Acquire and Accept Help, Passive Appraisal, and Reframing, respectively. These relationships certainly make sense
intuitively. Schools play a central role in helping the children during their formative years, so it is not surprising that suggestions from various school officials, especially teachers are presently helpful to mothers. Similarly, an ability to reframe stressful events so that they are more amenable to action, is a type of personal resource that we identified. The relationship between Health Professionals and Passive Appraisal, and the lack of a significant relationship between Community Agencies and the Mobilizing Family to Acquire and Accept help are more difficult to understand. However, it may be that while these categories are helpful to mothers, they are not used as effectively as they might, and perhaps tend to foster a feeling of powerlessness in mothers.

In part, the discrepancy between the type of resources we generated, which reflected internal (psychological) and external (social) familial characteristics, and the FIRM may be because, on closer examination, the FIRM appears to primarily focus on internal familial attributes, which are difficult to identify through the procedure that we employed here. Indeed, more than 35% of the resources identified in the interviews were of an external nature, which, as we found, are better suited to F-COPES. However, F-COPES is not properly described as a resource measure, in contrast, it is supposed to measure more general coping behaviours (McCubbin & Thompson, 1987).
Upon reflection, it would appear that the interview data would be better represented, quantitatively, by a test that combined aspects of the FIRM and F-COPES. Rather than having two separate tests, each of which appear to measure two different types of resources (internal and external), we would be better served by one test which encompassed both. Nevertheless, given the wide range of resource use identified by mothers in this sample, it is very likely that no one test would be able to accurately capture every families behaviour.

**Relationship Between the Qualitative Data and Other Measures**

Although we failed to find a significant quantitative relationship between overall resource use (as indicated in the interviews) and the degree of the stressor, others investigating the relationship between young mothers and their children have found a positive relationship between the two (Barakat & Linney, 1992). However, a possible explanation for our results may be that mothers with adult off-spring are generally failing to tap potential resources. This is probably because, as noted previously, some of the resources they need, especially community resources, are simply not available. This would also support one of the two interpretations of the finding that mothers' present levels of stress are related to increased interactions with friends and neighbours. Namely, that because of the lack of suitable community resources, mothers with high levels of
stress are forced to turn to friends and neighbours for help. However, as noted previously because we cannot determine causality this interpretation lacks power.

Similarly, in contrast to the findings of Prieto-Bayard (1993) who examined resource use among Spanish speaking mothers (the average age of mothers was 34.2 years) with young children (ages ranged from 37 to 147 months) who had developmental delays, resource use was not related to the age of the mothers. This may be related to a number of factors, including the limited sample size of this study (N = 28), and the fact that most of the mothers in our sample belonged to the same cohort group. That is, the comparison groups were not sufficiently different, and therefore there was little difference in the resources that they had been exposed to during their child’s lifetime (recall our impressions that past resource use was associated with current resource use). This cohort effect may also explain the finding, in contrast to Cameron (1979) who emphasized the important role of husbands in facilitating maternal adjustment to children with developmental disabilities, that family members were more frequently seen as helpful than husbands. It is likely that most of the women in Cameron’s (1979) sample were younger than the women in our sample, and so less likely to have grown up in traditional environments where the husband was the primary breadwinner and had little direct impact on the daily functioning of the family.
Similarly, in our sample, the mothers had other adult offspring who were able, in place of their fathers, to help them.

As noted previously, this study is one of the first to examine families with adult sons/daughters who have developmental delays, and so there are only a few other studies to which we can directly compare our results. Most other studies did not follow the children or mothers into mid and late adulthood.

Limitations of the Present Study and Suggestions for Future Research

Overall, the results of this study are mixed. Mothers appear to employ a diverse number of resources, however, at present these resources are not being adequately measured by existing psychometric tests (for example, the FIRM) designed to assess such resource use. Furthermore, it would appear that a test (F-COPES) designed, primarily, to measure another variable, specifically coping behaviours, is actually tapping internal and external resource use. As such, researchers are being hindered, via the use of inadequate psychometric tools, in their attempts to accurately study resources and coping behaviours amongst mothers who have adult sons/daughters with developmental delays living at home.

Possible limitations to the generalizability of the findings include a small sample size (N = 28) which limits
statistical power, a racial bias (all participants were Caucasian), a cohort effect, and a selection bias that may have resulted in the over-representation of the use of community agencies by mothers in this sample. In this sample, the latter issue is raised because mothers were recruited for the study through community organizations which were providing services to this population.

Social desirability, often an inherent problem with self-report inventories (Robinson & Anderson, 1983), may also have inflated the scores on the quantitative measures that we utilized. This may have served to potentially underestimate the extent of the relationship between the qualitative data and the quantitative data.

The results of this study underscore the importance of resources to members of this population and the need to enhance existing services. This follows from the relatively wide array of resources identified and the fact that most of the data reflect positive attitudes towards such resources. The enhancement of services should be accomplished via the creation of early post-natal intervention programs, and more postschool programs targeted towards adults, not just children, with developmental delays. Specifically, priority should be given to increasing the availability and flexibility of in-home respite care, improving transportation systems, and encouraging more young people, especially males, to befriend members of this population.
In addition, we must be careful, in an era where the trend is to streamline services, to maintain the diverse nature of resources available to caregivers. Although community agencies were especially emphasized by the caregivers in this study, other resources were also identified as helpful. Prieto-Bayard (1993) notes that different resources fulfil different needs. As a result, so as to ensure that we do not fall short of mothers’ requirements, we must guarantee that there are a number of different services available to them. Furthermore, we must not underestimate the capabilities of these mothers and their off-spring to successfully resolve the problems that they face without outsider intervention. As such, service implementation should be carefully matched to the needs of the user.

The discrepancy between the qualitative and quantitative findings re-iterates the importance of triangulating data, that is collecting data from qualitative and quantitative sources. Only when the data is collated in this manner can the researcher be sure of capturing the true nature of his/her sample.

In order to validate the findings presented here, more studies need to be conducted with members of this population. Ideally, a larger sample size should be employed so that researchers could conduct a longitudinal study, following mothers and their children completely through adulthood. In addition, like the study by Houser
and Seligman (1991), the analysis should be expanded to include the reactions of other family members, particularly fathers. Finally, attempts should be made to create a more suitable measure of resource use and availability within the population studied here.
APPENDIX A

PRIMARY DIAGNOSES OF CHILDREN \(N = 28\)

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<tr>
<td>Behr’s Syndrome</td>
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<td>3.6%</td>
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<tr>
<td>Cerebral Palsy</td>
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<td>3.6%</td>
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<td>Down’s Syndrome</td>
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<td>Hydrocephalus</td>
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<td>3.6%</td>
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<td>3.6%</td>
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<tr>
<td>No sex appropriate hormones</td>
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<td>3.6%</td>
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<tr>
<td>Not Known/Unclear</td>
<td>13</td>
<td>49.4%</td>
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</table>
APPENDIX B
INTERVIEW GUIDE

DIAGNOSIS
I'd like to take you back to the time you first learned that your child was mentally handicapped. Can you tell me something about how you found out?

-actual diagnosis/cause, age of child, when was parent told, who told parent, how was parent told, any explanation given, any suggestions regarding support, any prognosis given, compare with development today.

PARENTS: FEELINGS, REACTIONS, CONFLICTS
Could you describe some of the thoughts that went through your mind when you heard that your child was mentally handicapped?

7777 -feelings, length of time until acceptance, feelings today, how dealt with feelings, ability to discuss feelings with anyone, partner's feelings, marital relationship, any danger of marital break-up, was (potential) break-up related to child's disability, effects of having child with disability on marriage and other individuals.

CHILD: FEELINGS, REACTIONS, CONFLICTS
Has your child ever expressed any feelings about his/her disability?

-feelings not able to express, feelings acknowledged,
guidance/counselling regarding discussion of feelings, recognition of own limitations, any conflicts with child, how conflicts are resolved, easy to get along with, participation in decision-making.

**SIBLINGS: FEELINGS, REACTIONS, CONFLICTS**

What about your other children, did they ever express any feelings about having a brother/sister who is handicapped? -reactions, feelings acknowledged, guidance/counselling regarding discussion of feelings, willingness to share in responsibility of care for brother/sister, effects of having sibling who is handicapped, relationship today, share in care today, conflicts with brother/sister, how conflicts are resolved, if could repeat would change behaviour.

**EXTENDED FAMILY: FEELINGS, REACTIONS, CONFLICTS**

How did your relatives respond to learning that your child was mentally handicapped? -feelings expressed, reactions, support given, relationship with child today, level of support today, conflicts regarding child's disability, how conflicts are resolved.

**COMMUNITY: FEELING, REACTIONS, CONFLICTS**

How did your friends/neighbours, respond to learning that your child was mentally handicapped?
-feelings expressed, reactions, relationship today, lost relationships due to handicap, conflicts, how conflicts are resolved, parent's perception of change in community attitude.

WORK/DAY PROGRAM
Tell me what your child does during the day?
-If attends work/program goes daily, what child does there, any training, enjoyment, easy to get out of bed, brings own lunch, transportation, satisfaction with transportation, conflicts at program, suggestions for improvement.
-No work/program why not involved, would like to be involved, parents feelings regarding the same, difficulties having child at home, what would child enjoy?

SOCIAL/RECREATIONAL
Does your child have any friends of his/her own?
-how often do they meet, what do they do, do they require transportation, would like child to have more friends, is it hurtful for parent when child has no friends, would parent like child to go out more.

IMPACT
In what way is it helpful/not helpful to have your child living at home/in a group home?
-companionship, household chores, self-care abilities, physical problems, special diet, table manners, annoying habits, supervision required, easy/difficult to keep occupied, demands on parent's time, primary caretaker, emotional/physical strain, financial burden, level of understanding regarding money, supervision regarding finances, spending money, ability to buy own clothes, goes out alone, can be left at home alone, parents have difficulty going out alone, last family vacation.

RESpite Care
Do you now receive or did you ever receive any type of parental relief from a community agency?
- how often is service used, why discontinued, does current amount meet needs, have needs changed over the years, satisfaction with service, suggestions for improvement, conflicts with agencies, how resolved, preference for respite in home versus outside of home, awareness of agencies providing care, reasons service not used.

GROUP HOMES
How long has your child resided in a group home?
- number of placements, reason for transfer/change, satisfaction with care, suggestions for improvement, staff turnover, conflicts, how resolved, how placement changed
parent’s life.

Have you ever considered placing your child in a group home?
- reasons why/why not, any changes would like to see.

**SEXUALITY**

Has your child ever received any instruction/education concerning his/her sexuality?
- by whom, at what age, questions asked by child, parents’ feelings regarding sex education in schools/workshops, rights of child regarding sexuality, sterilization, birth control, child’s ability to raise a child, parents’ fears regrading pregnancy/marriage/sexual activities.

**FUTURE**

Looking ahead, what would be the best of all positive outcomes for the future?
- living arrangements, job, role of siblings, any arrangements regarding guardianship, parents’ concerns/needs, parents’ fears, suggestions on how agencies could make things easier.

**GENERAL**

Is there anything else that you would like to talk about that I have not covered or that you want to discuss further?
APPENDIX C
SEGMENTING RULES

1. A maximum segment is the statement made in between two utterances of the other speaker.

2. A minimum segment is some simple response such as "hm hm" made to the other speaker.

3. If 2 people talk at the same time and one's speech is broken up on the transcript, then include the continued information as part of the same segment. For example:
   
   (Segment 1)
   M-/And I think.....
   D-hm..hm..

   (I cont'd) M-that they should go./

4. Use sentence structure as a clue.

5. If one person responds to the other and then continues to say something else, count this as two segments. For example:

   M-/Do you agree?/
   D-/Yeah.//I sure think that she should find a job./
COMMUNITY AGENCIES:

"I think they [in-home respite care] do a great, fill a great service for them...coming into the home and helping us."

"There was something to look forward to for her and it did me good to be on my own during the day, I could do then as I wanted to like and I'd say yes, [the community workshop] that was the best."

"Yes it's [the community workshop] a great, it's a godsend really. I don't know what I'd do without it."

EMPLOYERS:

"Although I did a lot of my work at home, so that was helpful...yes, I could always bring...work home and really work my own hours and I was very lucky that way."

FAMILY MEMBERS:

"All through my life, my family has been very supportive, by this I mean my mother and my brothers, I mean...they especially so, so that..."

"My own family probably [have been the most helpful]...we've never been into agencies that much...we always had enough family."
"And like I say, I can't stress enough, I'd very good encouragement from my own people."

**FRIENDS/NEIGHBOURS:**

"And then sometimes I get on the phone, with my friends and you know we tell jokes...that makes me feel better, yes."

"Like the next door neighbour here...you know anything that he [son] wants she's taken care of him...that's helpful...they've always been..."

"...so later on my neighbour called me...she was so happy to take my son...and she's pretty good...with kids..."

**HEALTH PROFESSIONALS:**

"...and our doctor is always very supportive...he is always there and I can take any amount of his time..."

"...I really feel that all the work, the social worker that has come here have been great, oh yes."

"Well I think the doctor...is very supportive of me...willing to give me all kinds of time and help with him..."

**HUSBANDS:**

"And I think we've helped each other because without him I don't know, I wouldn't have been able to do what I do,
I know..."

"Oh, I'm sure it [marital support helpful] is, yeah, oh I'm sure it is...I just think that we, you know, it's probably one of the things that pulled us even closer together and it gave us such a strong solid base..."

"With this type of thing he could never have done it without me and I could have never done it without him."

INFORMAL NETWORKS:

"Talking to other parents [with children who are developmentally delayed]...we understand...you understand each other."

"But when you talk about it, it makes you feel better because you know, you let it out instead of holding it in, you know, and like before we did this [met with other parents who were in a similar situation], I was all alone and you know..."

"[mothers group have been helpful] better than any paid agency could ever have done, because we were there for each other."

PERSONAL RESOURCES:

"Well, I think by having a positive attitude, I think that's really important."

"I think I am [a strong person], I must be like my mother, my mother was a strong person....they tell me that
I'm just like her...some people let things get right to them and I guess I didn't...I think that's how I coped through the years, just not letting it take over me."

"He was my child and I thought that I, you don't give up on kids. You keep fighting for them as long as you can..."

**RELIGIOUS FAITH:**

"And of course, you pray, you know. I'm not denying that."

"Yes, I'm not a zealot, as you say, but I have felt a lot of support from above and I'm very grateful for it."

"My faith, my beliefs [have been helpful]. I've never, I don't believe that God gives you anything that you can't accept, that you can't handle."

**SCHOOL:**

"Well, the school was the most helpful..."

"I would say that people that worked at the school where she went...were really helpful..."

"They [school] would seem to know his faults or his good points and they'd be able to talk to you about them. And then they would advise you what they thought to help, I found them pretty good, yes, through the years."
# APPENDIX E

**FREQUENCY OF CATEGORY ENDORSEMENT BY EACH MOTHER**

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REFERENCES


VITA AUCTORIS

Elizabeth Jane Hall was born on June 7, 1971 in Glasgow, Scotland. In 1987, following completion of her O-Grades, she emigrated to St. John's, Newfoundland where she attended Prince of Wales Collegiate for a year. In 1988 she enrolled at Memorial University of Newfoundland and graduated with a Bachelor of Science (honours) degree in Psychology in May, 1993. At this time, she was also awarded the President's Bronze Medallion for Excellence in Psychology. Since September 1993 she has been enrolled in the doctoral program in adult clinical psychology at the University of Windsor.