

THE UNIVERSITY OF MANITOBA

SOCIAL NETWORKS AND SOCIAL SUPPORT IN  
FAMILIES SUCCESSFULLY ADJUSTED TO THE  
BIRTH OF A DEVELOPMENTALLY DELAYED CHILD

A PRACTICUM REPORT PRESENTED TO THE FACULTY OF  
GRADUATE STUDIES IN PARTIAL FULFILLMENT OF THE  
REQUIREMENTS FOR THE DEGREE OF  
MASTER OF SOCIAL WORK

FACULTY OF SOCIAL WORK

BY  
CHRISTOPHER HAUCH

WINNIPEG, MANITOBA  
MARCH 1990



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**BY**

**CHRISTOPHER HAUCH**

A practicum submitted to the Faculty of Graduate Studies  
of the University of Manitoba in partial fulfillment of the  
requirements of the degree of

**MASTER OF SOCIAL WORK**

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## Preface

The following is a report on a practicum in applied research. The tasks which it outlines relate to an exploratory, human service evaluation exercise. As such, unlike most reports of practica, a study is described, rather than an actual human service intervention.

By its nature, then, this report bears some similarity to a thesis. There are some important differences, however. For a start, the object of the practicum was to provide the writer an opportunity to acquire skills in applied research. Thus the report, while having the requirement to provide reasonably coherent findings, is first of all mandated to describe educational process and outcomes. The discussions on expected benefits and conclusions, then, relate to educational, rather than research, goals.

Second, during both the study's design and implementation the writer enjoyed the benefit of working directly with two co-investigators--one fellow student and a project coordinator. This arrangement is not unique to practica, of course. Students preparing theses may occasionally work on research teams, and be responsible for one circumscribed portion of a larger study. Rarely, though, are the planning activities of all investigators coincident, or as mutually influencing as they

were in this study. In the manner of applied research, the writer had central, but not exclusive, responsibility for one minor area of the project, and at the same time was required to contribute the study as a whole. This will account for occasional references to certain elements of the larger project which were not directly connected to the topic of this report.

## Chapter One

### Practicum Objectives

#### 1.1 Aims of the Study

The present study was performed in the context of a broader research project focussing on coping and adaptation in families with disabled children at home. In that project, a sample of families was selected on the basis of exemplary adjustment to the circumstance of caring for a developmentally delayed infant. Mothers and fathers were interviewed, with a view to uncovering recurring themes in family organization and coping style. The central goal of the study was to generate testable hypotheses on the origins of family strength. While the study was thus largely exploratory, scale norms permitted some quasi-experimental, between-group comparisons.

The study examined a variety of dimensions of individual and family functioning. Basic demographic information was collected, as were data on the nature and magnitude of each child's disability. As is often done in studies of families with disabled children, child temperament was examined (by standard measurement of mothers' perceptions), and mothers were tested for depression. Beyond this, both mothers and fathers were interviewed on marital satisfaction, as well as on patterns of family functioning and coping style. Parents also described the impact which the child had had on the family, and gave accounts of their

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experiences with the professional helping system.

This report describes findings on extradomestic organization, specifically, parents' social support networks. Three structural characteristics of families' social networks were assessed--size, density (extent of association among network members), and boundary density (overlap in membership of spouses' networks). Further, using mothers as focal respondents, network membership was examined as to dimensionality (variety in support provision), sex distribution, frequency of contact, relationship (in the case of family), and length of relationship (in the case of friends). Finally, standardized measures were used to test mothers' perceived social support from family, and families' ability to seek out and accept support in times of difficulty.

## 1.2 Expected Educational Benefits

As mentioned, the objective of the practicum was to provide experience in the planning and implementation of a study in the human service field. While this posed few constraints on the selection of topics, it did present certain important design, and hence educational, requirements. By the nature of the study, subjects were contacted on the basis of their involvement in a particular social service. The service itself was only a peripheral object of interest to the research, and hence a formal evaluability assessment was not believed appropriate. Still, it was necessary to review the service's intake and recording

procedures, in order to clarify general characteristics of the sampling frame.

The involvement of the service had a direct bearing on the study itself. While it was hoped that the study would yield findings of interest to researchers working with families, it was also necessary that it address direct concerns of service providers, and most importantly of respondents. It was important, then, to learn means of consulting with involved parties, to ensure that the study would not fail on the basis of its being irrelevant, or excessively intrusive. The instrument which was used was quite long, and required respondents to disclose a good deal of personal information. Discussions with service staff, and with potential respondents during pretesting, provided valuable information on how the instrument might be presented, and which items might be added or modified.

The greatest share of learning requirements centred on research design and implementation. The study was performed by a team. Therefore it was necessary to participate in general planning as to the relationships among the various measures, as well as of administrative issues such as the scheduling of tasks, budgeting and so on. Following a review of relevant studies an omnibus survey on social support networks was prepared, incorporating both standardized measures and measures designed for the study.

Supplementary instruction was required in the areas of survey design, data analysis (particularly as it related to

standard measures), pretesting procedures, and interviewing.



## Chapter Two

### A Review of Literature Concerning Stress, Coping, and Social Support in Families with Developmentally Delayed Children at Home

#### 2.1 Introduction

The task of assembling and describing a body of work germane to the present study has proven a surprisingly difficult one. For a start, entering what on the face of it appears a substantial literature, one quickly finds oneself hard pressed to find much in the way of directly relevant research reports. Very few investigators, it turns out, have chosen to combine a focus on home care of mentally retarded children with social networks and social support.

Worse, the research which does exist in this area does not easily nest in any single, theoretical tradition. Rather, it is the product of two histories. On the one hand, it represents important innovation in network analysis; on the other, more evidence of the role of general, parental coping in success of home placement. By opting to describe it in the context of either, one is forced to place diminished emphasis on a whole, broad base of knowledge.

This section, then, contains an invariable bias, perhaps to its detriment. The choice is made to refrain from substantially reviewing the broader network literature. This is not done

arbitrarily. In an important sense, within the literature on social networks and social support, home care of mentally retarded children is essentially a case study. That is, there is nothing inherent in the network literature which specifically requires that home care be investigated.

The converse, however, is clearly not so. The history of research into family care of mentally retarded children reveals an increasing, if begrudging, acknowledgement of the importance of complex, social systems. Research into social networks and social support in families of mentally retarded children has therefore flowed far less from an interest in network analysis per se, than from very real failures in models which traditionally have ignored network variables.

This review, then, focusses principally on the history of family care research, and secondarily on the probable role of social networks and social support in that highly specialized, social environment.

## 2.2 On the Benefits of Family Care of Mentally Retarded Children

There is little argument that the family is central among the resources available to mentally retarded children. Despite the vagaries of public sentiment, in fact, the family in North America has always provided the greatest sheer quantity of services to the overwhelming preponderance of this population (Farber 1968:187). In contrast, it is a far less straightforward matter to actually demonstrate the benefits which accrue from that

resource. This is so for a variety of reasons, among them that the criteria which require to be invoked are multidimensional. We are speaking of values, as they pertain to human, social phenomena. And thus it is never possible to delimit the global question: "beneficial to whom...and in what way?"

Moreover, at this particular, historic juncture, we are speaking of phenomena which are neither remotely static, nor free of controversy. More so than in any other period, mental health professionals in recent years have advocated the expanded use of family over institutional care (Willer, Scheerenberger, and Intagliata 1978), citing not just an amalgam of known ethical, fiscal, and therapeutic benefits, but hypothetical ones as well. Their arguments have been given effect by law. Throughout the course of the community mental health movement major court decisions, one after another, have called for 'least restrictive' treatment modalities and environments for mentally retarded persons (Morris and Brown 1983; Katz-Garris and Garris 1983). Accordingly, social planners have become increasingly willing to explore community-based service options. And as their willingness has translated into action, albeit in disparate ways, the full scope of family care benefits has only gradually, and incompletely, been revealed.

All the while, apprehension as to the supposed perils of the process has radiated from public, scientific, and human service constituencies. Notably, there has always been uneven commitment to the very planning principle which seeks to bring

family care benefits to full fruition: the principle of normalization. This historical anxiety requires at least brief discussion, since in a sense it has traditionally helped define the practical limits of family care. That is, the freedom of such benefits to be realized has always been linked to the perceived, potential workability of normalizing programmes. Some forms of opposition to the concept have faded, and thus benefits which could not have obtained formerly now do. Others are seemingly intractable. And whether valid or not, it is likely that they will have important influence on family care's achievements.

Most succinctly defined in the work of Wolfensberger (1972; 1980a; 1980b), the principle of normalization addresses the usage of segregating care, care of the sort which promotes abstention from natural living patterns and environments. It is a planning principle in human management, a kind of global programmatic directive, which in the broadest sense is informed by two premises. The first of these is that mental well-being is nourished by lifelong involvement in normal social interaction. The second, a corollary, is that the disabling impact of impairment is enhanced by the pejorative, and therefore isolating, perceptions of those not afflicted.

In relation to both these premises, care which utilizes social isolation is considered problematic a priori; both direct, iatrogenic effects, and social stigma, are said to proceed from it. As a remedy, the normalization principle urges "utilization of means which are as culturally normative as possible in order to

establish and/or maintain personal behaviours which are as culturally normative as possible" (1972:28). Here, a formal helping system is advocated. But unlike its predecessors, the normalized system designates social normalcy as a process goal. In essence, by the equating of process with outcome an optimal level of care is said to be achieved. A complementary, intended effect is the education of noncare recipients, and hence the destigmatization of disabling conditions.

As elsewhere in the community mental health movement, proponents of normalization in the mental retardation field have advocated deinstitutionalization. More specifically, the prescription in this case takes the form of supporting families (presumptively the most normalizing social environments) or family-like settings in lieu of traditional, residential care. For understandable reasons, however, implementation has not been altogether uneventful. Parents of mentally retarded children themselves have resisted, reporting that institutions are likely to provide the best care possible (Meyer 1980). This conservative reaction is not surprising, when one considers that the painful decision to relinquish care of a child may have been grounded in a traditional treatment paradigm. As Mesibov and La Greca have put it "...human emotions, especially in regard to one's children, are not as malleable as trends in community programs" (1980:5).

Or perhaps it is more accurate to say that support is qualified. Ferrara (1979) reports that often parents of institutionalized, mentally retarded children respond favourably

to normalization as a planning principle, but express resistance to it as it applies to them personally. Seltzer (1984) demonstrates that much the same phenomenon is evidenced in neighbourhoods which are slated for community residences. Moreover, the author shows that at this level the polarity in sentiments--of acceptance in principle vs. dissension against the fact--is only intensified by local public education efforts.

Opponents of normalization in the academic and professional helping communities have tended to be somewhat less diffuse in their apprehensions. Here, of course, the importance of normalcy in social life has always been generally endorsed. However, some view this construct solely as a treatment outcome, and discount its applications as a technology. In one of the most vociferous, popular criticisms of normalization Throne (1975) maintained:

To speak of normalizing the retarded by treating them normally is a contradiction in terms; treating them normally will leave them functioning as retarded. Retarded by definition means retarded under ordinary conditions. Only extraordinary conditions--nonnormal can result in diminishing retarded states, i.e., making the retarded more normal. (23)

In the way of a partial concession, others argue that mentally retarded children develop socially, as well as intellectually, at varying rates. Hence, social milieus, and expectations, ought not arbitrarily be tailored to external notions regarding normalcy--so the reasoning goes--but rather designed with sensitivity to the needs of each care recipient (Hendrix 1981; McCarver and Cavalier 1983).

Even so, as regards these kinds of reactions Wolfensberger's forecasts may yet be vindicated. Feinstein (1986) provides interesting longitudinal data on deinstitutionalized, mentally retarded children and adults and their families. A large facility in Pennsylvania was closed, as a result of a ruling in a class action suit, and close to 800 were relocated to small community residences. Initially, family members reported serious apprehension with the arrangement. But after a period of three to five years, most seemed to feel the reverse, expressing substantial satisfaction. Family-based care was not implemented in this case; nonetheless, the observed relationship between relatively long-term experience with, and support for, normalized treatment options, does provoke optimism.

Unfortunately, it has been difficult to locate a study of this kind reporting on neighbourhood reactions over time. Such a research would in any case be suspect, however, in that given the current social policy environment, severely resistant neighbourhoods are often able to block community residences in the planning stage (Seltzer 1984).

As to the residual professional opposition, it will likely require the orderly accumulation of outcome data to realize any progress. At the moment, though, empirical data in support of family care is not easily come by. One reason is unalterable--namely, the principle is in no small way value-based. Normalization implies certain ethical precepts (for example, every child has a fundamental right to live in a family), and as such

summons evaluation on more than just scientific criteria (McCord 1982). Another is temporal. At this stage of its development, normalization does not provide a unified technology. Wolfensberger (1972) has outlined a number of fairly global standards for community care. But the question as to what new support services are likely to be required in years to come remains in many ways unanswered (Intagliata, Kraus, and Willer 1980).

Despite the turbulence of this issue's social history, it can be argued that empirical support for the expanded use of family care does exist. There are substantial limitations to it, however. To begin with, controlled comparisons of institutional and family care are not available in any great abundance. Notably, the philosophical underpinnings of normalized service delivery have tended to be more moralistic in character than quantitative. And its initial prescription, the closure of institutions, has proceeded as much from a consideration of economics, and human rights, as any other factor. In sum, for a number of reasons proponents of family care have not had to await the accumulation of between-group investigations in order to make compelling, and effective, arguments. Their more pressing question has always been "what can be done to make family care work better than it does?" (Innovations around this question will be the subject of subsequent sections.)

Moreover, the research which does exist has been plagued with a host of confounding, historical factors. For a start,



concern as to poor conditions in institutions has led, in recent years, to structural improvements in institutional care (Willer, Scheerenberger, and Intagliata *ibid.*). Second, as already mentioned, community-based treatment alternatives are themselves in a process of (ofttimes divergent) evolution. As such, they have so far failed to produce a unified treatment technology (Campbell and Bailey 1984). Third, in addition to ongoing change both institutional and community care alternatives, random assignment at the point of diagnosis has rarely been possible. An ideal research would involve following children's development only after matching had been done on such factors as nature and magnitude of impairment. In practice, however, myriad considerations enter into referral decisions, including apparant stability of the family in question. As it happens, most controlled studies have focussed on deinstitutionalized adults; and in consequence, our knowledge as to the effects of family care on child development is limited.

Finally, even to the present there is debate as to how health ought to be calculated. Tests of mental and social competence, for example, vary among the studies. Worse, the process whereby worth, or meaning, is assigned to various human attributes has been influenced by ideological commitment. This is especially problematic inasmuch as divergent, noninstitutional treatment settings have seemed to wield specialized effects, producing improvement in one or two broad dimensions of functioning, often seemingly at the expense of another. Evidently, then, no single element of the subject matter has been impervious

to change processes and philosophical disagreement. And therefore even quantitative research has failed to reflect unified, theoretical traditions. We proceed with caution.

In an early study, widely cited to the present, Stedman and Eichorn (1964) compared institutionalized and home reared mongoloid infants on growth and development variables. A matched sampling process was used, with outside social service personnel referring 10 diagnosed cases to an experimental, institutional setting. (The setting was intentionally 'enriched', having a better staff: child ratio, physical characteristics, and play materials than most facilities of the day.) Once the children had resided in the setting for a maximum of 37 weeks (referrals having been staggered in time), a similar selection process produced a like-sized, home-reared sample matched by age and general state of health. Members of each group were administered standardized tests of social and mental competence and motor performance. As well, basic anthropometric measures were taken. Despite the low sample size, data suggested that home-reared children were substantively superior to their institutional counterparts with respect to both intelligence and social competence. The authors found no statistically significant differences in motor performance; physiological differences were negligible.

Stedman's and Eichorn's study is unusual, in its treatment of mental test performance as a dependent variable. Most research of the last decade has tended either to report I.Q.--or

other supposed measures of innate, intellectual capacity--as incidental information, or hold them constant. Instead, the common focus is on changes in social/behavioural competence. Three broad subconstructs have emerged most prominently; 'self-care skill': the ability to provide basic care for oneself, as in eating and dressing; 'adaptive behaviour': normative, social behaviour, and the absence of ostensibly deviant behaviour; and 'community living skill': facility at complex tasks requisite to independent living, money management, for example (Gully and Hosch 1979; Berk 1980; Reid 1983).

Eyman and Arndt (1982) provide interesting data concerning adaptive behaviour and life-span development. A large sample was examined, which included both longtime community (in own home, or family care setting) and institutional residents. (Mean I.Q. was 36 for the first group, 26 for the second.) Members of the community based group displayed markedly superior scores on adaptive behaviour scales. However, each group showed growth, over the ages of 5 to 50 years; moreover, when scores were plotted for each group, to illustrate age norms, the graphs which resulted were similarly shaped. Community based care would seem to enhance adaptive behaviour growth, then, but have little effect on the developmental sequence of that construct.

Willer and Intagliata (1982) provide corroborative data in a study of formerly institutionalized adults, who had resided for at least two years in family care and group home settings. Samples were roughly matched, to the extent of producing similar

mean age and I.Q. Each group showed progress in community living skill, with group-home residents ahead of their family based counterparts. Family care residents were markedly superior in adaptive behaviour growth.

Despite the findings, the apparent growth in adaptive behaviour of group home residents may have little bearing on subsequent placements. Reagan et al. (1980) examined the progress of deinstitutionalized juveniles, labeled as 'behaviour problem educable mentally retarded'. The authors showed that with a modicum of case planning, placement stability in home settings was impressive (73% at the end of 18 months). In addition, over the same period subjects placed in group homes and foster homes were successfully relocated to less restrictive settings. No behaviour scales were administered, but by way of regular contact social workers ensured that at the very least placements did not exacerbate behaviour problems.

Berkson (1981) suggests that positive change in social behaviour is transient, or rather evidenced solely in the living settings alleged to produce it. Young adults who lived with their families, independently, or in shelter-care homes were matched (by age, sex, and I.Q.) and tested on various indices of social behaviour in sheltered workshops. No differences were observed. Of course, the finding cannot discount the argument that nonnormative settings are likely to elicit nonnormative behaviour. Mainstreaming, for example, (the integrating of disabled children into mainstream schools) has been amply studied, and demonstrated

to maintain growth in social development (Blacher-Dixon, Leonard, and Turnbull 1981). Nor is the finding all encompassing. Normative--ie., familial, rather than institutional, settings, have been found to elicit growth in certain linguistic subskills, with apparently permanent results (McNutt and Leri 1979; Thoman 1981).

Reliable information concerning the more mundane issue of cost-benefit is even sparser than that pertaining to health outcomes. Again, the major reasons for this are the newness of family care as a legitimate option to institutions, and the variety which exists among community based service systems. There is reason, of course, to suspect that family care will be less expensive, in the long term, than institutional care. Shortly before institutional admissions had peaked in the United States, Dybwad (1964) reported that nearly one-third of all monies directed to programmes there for the mentally retarded were being spent on those 4% who received in-patient care.

That this unbalanced apportionment reflects actual waste is supported by consideration of at least two factors. First, given our current clinical assessment procedures, the raw prevalence of mental retardation is destined to stay fixed. As Saunders and Silverman (1982) remind us, the condition is in most cases diagnosed with an I.Q. test, an instrument which "...yields a standardized score, the norms for which are periodically revised, so that the proportion of the population who

are labelled retarded remains constant, absolute levels of ability notwithstanding" (107). Second, in recent years community based programming for nonretarded, psychiatric patients has been amply demonstrated to be cost-effective, as well as therapeutically sound (a good literature review appears in Kiesler 1982).

Nonetheless, detractors argue that the transfer of monies to institutional support personnel ramifies positively throughout the economy as a whole (Bernard 1979). A more serious concern, however, has to do with the paucity of evaluable (ie., comprehensive) service systems per se. Given that we have only limited knowledge concerning families' service usage patterns, one may well claim that family care generates all manner of hidden expenses (cf. Shadish 1984).

Despite this very legitimate caution, a few efforts at defining and pricing closed systems are encouraging. Boas and Retish (1977) report on a detailed evaluation of small group homes in Iowa, whose per diem seems at least at par with those of area institutions. Burish (1979) provides somewhat more optimistic results, in connection with his research of Cottonwood homes in Kansas. Intagliata, Willer, and Cooley (1979) performed a critical costing out of expenses related to family care in New York State. All services considered, care provided by natural families seemed many times less expensive than either institutional or group home care. Similar, albeit more tentative, findings have been reported by Valerie and Agosta (1985) on direct cash transfer programme to families in Michigan.

### 2.3 Unidimensional Studies of Stress and Its Outcomes

While research concerning the advantages of family care has been encouraging, there has been considerable concern as to the persistent, residual failure rates of family care placements. As noted, Reagan et al. (ibid.) found that even under supportive conditions, relocation to more restrictive settings was sometimes necessary. After 18 months, 15% of those placed in natural homes were moved to community residential facilities, 5% to institutions. This is more or less consistent with earlier findings. Bishop (1957) reported that some 31% of family care placements were likely to result in reinstitutionalization (consider that there were relatively few community based alternatives at the time).

One artifact of this phenomenon is a fairly rich history of empirical investigations having to do with stress in families. Predictably, it has produced competing paradigms. On the one hand, one finds some modest evidence of a systems orientation. Particularly in the more current research, the complex, transactional character of family life has been described. For the most part, however, the dominant theoretical tradition has been defined by a stress-reaction model, one largely framed by the premises: 1) living in the family home a mentally retarded child wields an aversive impact on normal family functioning, and 2) the nature and magnitude of that impact derives directly from the nature and severity of his/her disability. Thus we find

epidemiological studies attributing reinstitutionalization to specific child characteristics. And from a more clinical position, many others report on the common 'pathologies' which arise in and among family members.

In this section, research of the latter type is considered. Presently, and in subsequent sections, it is argued that unidimensional studies have failed to produce unified, predictive models, and that this failure is attributable to at least three, immense oversights. First, the children of interest have tended to be treated as mechanical, stimulus producers, rather than as intelligent participants in complex social environments. Second, the importance of family coping styles has been overlooked, in the search for universal, stress-reaction typologies. And third, the research has typically been synchronic; rarely have families been followed over time.

A number of investigations, in the last two decades, have tested child characteristics for their power at predicting family placement breakdown. So far, age, sex, and I.Q. seem to be unimportant, both independently and in combination. A weak association has been demonstrated between severity of attendant medical problems and reinstitutionalization (Seltzer and Krauss 1984). Indeed, only one characteristic has shown any real promise. In a review of the research in this area, Crawford, Aiello, and Thompson (1979) conclude that maladaptive behaviour is the single most powerful predictor variable.



As the term implies, maladaptive behaviour is the designated, polar opposite of adaptive, or normative, social behaviour. Thus much of the research literature presumes the existence of a stable continuum. Within that continuum behaviour is conventionally assessed, by standardized instruments, along at least two, broad subconstructs--personal independence and social responsibility (Lambert and Nicoll 1976; Holman and Bruininks 1985)--each subsuming a spectrum of age appropriate, adaptive skills. Clinical cuttings points are subjective, being intended to roughly distinguish behaviour repertoires which substantially fail to meet the expectations of performers' age and cultural groups (see Holman and Bruininks *ibid.*:73).

That this variable has emerged as a predictor of family placement breakdown is not, at least on the face of it, surprising. Parents, when asked to rank problems encountered in the course of caring for their retarded children, list 'disobedience', 'stubbornness'. and 'noncompliance' as being the most pressing, placing these ahead of even basic care-related issues (Tavormina, Henggeler, and Gayton 1976). The prevalence of maladaptive behaviour has been established to be markedly higher among institutional populations than community based ones (Eyman and Call 1977). And among all variables which figure into institutional placement requests for persons under the age of 21, behaviour problems are the most frequently cited (Tausig 1985).

Professional helpers' initial responses to the discovery have come as no surprise either. Notably, they were to posit that

maladaptive behaviour caused resinstitutionalization, and then use that argument to inform a technology. Researchers and treatment personnel have recommended that adaptive behaviour measures be used to guide treatment (Allen et al. 1976) and referral decisions (Barton, Brulle, and Repp 1982; cf. Beck and Joiner 1982). Training in behaviour modification approaches has been widely provided to parents, in efforts to obviate institutional readmission (Heifetz 1977; Altman and Mira 1983).

There is, however, much reason to suspect that these efforts may be premature. A number of studies have attempted to expand the causal sequence, by exploring the etiology of maladaptive behaviour. What emerges from these are the beginnings of a complex, transactional model. Cohen et al. (1977) showed that maladaptive behaviour was exacerbated by interinstitutional relocation, and thus demonstrated that the construct had a situational loading. Zigler and Balla (1977) described nearly two decades' research on the effects of institutions on mentally retarded persons. The authors emphasize that behaviour problems are related both to preinstitutional experience--stability of prior home life in particular--and characteristics of the treatment setting itself.

In an intriguing research project, Intagliata and Willer (1982) collected data on a large sample of mentally retarded children and adults living in community settings. The authors divided their sample in the manner of a 4 cell matrix, with one axis distinguishing subjects on the basis of residence (group home

or family care setting), and the other on whether or not their stay in their respective settings had ever been interrupted by a failure, or reinstitutionalization, experience. Data showed that on balance, former returnees could be distinguished according to residence, on the basis of maladaptive behaviour. In addition, though, returnees could in turn be distinguished according to residence, on the basis of the style of behaviour which occasioned the temporary discharge. Each setting, then, seemed to have its own particular weakness, with respect to the management of certain types of behaviour problems. The authors conclude that "...client characteristics and residential setting relate in an interactive fashion to influence placement outcome..." (38).

A somewhat corroborative finding appears in the work of Clark, Baker, and Heifetz (1982). Outcome data were gathered in connection with a behaviour training programme for parents (of interest were posttraining knowledge of behavioural principles, and constancy of application). The authors discovered that the degree of ostensible, longterm success of behaviour training programmes could be predicted from parent variables, in particular performance during training sessions. Moreover, outcome was found to be wholly independent of severity of children's behaviour problems.

Clearly, then, there is an association between maladaptive behaviour and reinstitutionalization. That this finding is at all useful, however, remains a matter of debate.

Much of the current research suggests that family placement breakdown results from complex, transactional events, perceptible only at the level of family systems. Thus, our ability to predict and prevent it, in specific instances, will likely be best enhanced by models which consider a multiplicity of variables.

Research, of the stress-reaction tradition, concerning the effects of home placement on family members has tended to suffer many of the design weaknesses already mentioned. Oddly, though, one of the earliest, substantive contributions to this literature was fairly broad-based in its focus, and probably ought to have served as a starting point for ecological investigations. Caldwell and Guze (1960) interviewed mothers and siblings of both institutionalized and home-resident, mentally retarded children. (Sample matching was done on the basis of characteristics of the retarded children.) Mothers were administered standardized health questionnaires, and measures of attitudes pertaining to child rearing. Siblings received vocabulary testing, and measures of manifest anxiety. Both mothers and siblings participated in non schedule-structured, psychiatric interviews, in which topics circulated around the experience of having a mentally retarded family member.

Analysis of standardized measures failed to reveal differences between the groups, along any of the dimensions considered. An interesting difference between siblings, however, was evidenced in open-ended interviews--one evidently foretelling

of Wolfensberger's ideas on the perpetuation of stigma. On balance, siblings tended to reiterate the views of their parents regarding placement decisions. In fact, most seemed largely adjusted to whatever arrangements had been made, and were inclined to cite the inherent disadvantages of alternative modes of care. The authors conclude "...adolescents and pre-adolescents who have had the experience of a mentally retarded child in the family are generally adaptable and...can mold their value systems in this matter to conform to the family status quo" (860).

The finding clearly underscored that the nature of family systems, and adaptation processes, were central to the phenomena of interest. However, historically this study had only limited impact on subsequent theory construction. What followed were vastly more quantitative, and focussed, investigations, each squarely grounded in the expectation that a host of negative outcomes of family placement only awaited to be revealed. In an influential study, Cummings, Bayley, and Rie (1966) interviewed mothers of mentally retarded, chronically physically ill, neurotic, and healthy children (respondents were matched on various demographic characteristics). Using a battery of standardized and projective measures, the authors argued that mothers of mentally retarded children experienced inordinate stress, were generally depressive, and suffered severely compromised self-estimation. So it went, they derived only marginal pleasure from their children; and thus their feelings towards them were in perpetual conflict, vacillating, in even

measure, between hostility and overprotectiveness.

The findings were bleak. But they aroused interest in the possibility that child characteristics could be linked to specific pathologies. Encouraged, Cummings (1976) attributed similar traits to fathers of mentally retarded children. Frodi (1981) proposed that mental and physical abnormalities in children were "aggression facilitating stimuli" (341), parents' predisposition to violence notwithstanding. (More correctly, her assertion was that the relevant predisposition of parents was not aggressiveness, but rather incompetence at arresting the severe, aggression-evoking behaviour typical of handicapped children.) Beckman (1983) showed that child characteristics, particularly social responsiveness, temperament, and need of extra caregiving, correlated with parents' reportage of stress.

In a study concerning the origins of stigma, Redner (1980) demonstrated that the actual behaviour of mothers of handicapped children elicited negative appraisals from others. Later, in an effort to explain how stigmatization ramified through family systems, Serbin, Steer, and Lyons (1983) showed that mothers tended to grossly underestimate the competencies of their mentally retarded children.

Research concerning the effects of home care on siblings is not abundant. Such as it is, though, it tends to contradict Caldwell's and Guze' (ibid.) early findings that suggested that siblings were fairly adaptable. Farber (1968) proposed that stress on siblings became manifest, gradually, over the course of the

family life-cycle. With time, even first-born, mentally retarded children assumed the status of youngest sibling. In consequence, younger siblings were propelled into a superordinate status, causing them to assume adult-like caretaking functions prematurely, and accordingly interfering with the normal progress of their relationships with parents. Fowle (1968) provided corroborative data, in a study of families whose children lived either at home or in institutional settings. Farber's birth-order hypothesis was not vindicated, however. Instead, the author's findings suggested that role tension occurred in all siblings, and in fact tended to be most severely evidenced in the case of eldest, female children.

Research into the effects of mentally retarded children on marital integration is also sparse, and fraught with controversy. Fowle (*ibid.*) reported that there were no significant differences between couples, in the study described. However, conflicting results have accrued from alternative designs. In a comparison of parents of mentally retarded and normal children, Waisbren (1980) made observations similar to those of Fowle. Friedrich and Friedrich (1981), on the other hand, found significant differences, and posited that diminished marital satisfaction was both a cause and consequence of the stress associated with parenting a handicapped child.

Later, Crnic, Friedrich, and Greenberg (1983) commented that this discrepancy was likely a reflection of sample

differences. Children in the Waisbren study were appreciably younger than those in Friedrich's; thus the two studies may have simply focussed on distant points on a developmental continuum.

Stress-reaction models have tended to fare most poorly in application to family systems. Indeed, at this level the literature all but ends--notably, at the point where the transactional quality of human relations is inescapable. One finds some evidence to suggest that families who care for mentally retarded children experience a slightly increased prevalence of crisis over comparison families (Willer, Intagliata, and Atkinson 1981; Wikler, Wascow, and Hatfield 1981). But for the most part studies of family stress, at least those purporting a unidirectional causality, are rare, and not likely to be very complex.

One important exception appears in the work of Jean Holroyd. In an ambitious effort, Holroyd (1974) proposed a mammoth, amalgamated measure, by the use of which, it was claimed, one might capture a whole spectrum of the supposed "psychological costs" of caring for a handicapped child (92). As its title, The Questionnaire on Resources and Stress (QRS), suggested, the measure freely tapped a variety of hitherto dependent and independent variables simultaneously. Some 15 scales were included, under the diverse headings "Parent Problems", "Family Problems", and "Problems of the Child" (ibid.).

From its appearance, the scale seems a kind of MMPI for



family functioning (or rather, barometer of the malaise 'family care of the handicapped'). And in fact, this has always been its stated intent. Its most intriguing application, however, has been as a research instrument, as a device for exploring relationships within its own data. In this connection, Holroyd and Guthrie showed a fairly typical association between certain "child characteristic" and "parent pessimism" subscales (1979:737). Friedrich, Greenberg, and Crnic corroborated the findings, in the course of producing a short-form of the QRS, and argued the concurrent validity of "Parent Family Problem" subscales by showing correlations with the Beck Depression Inventory (1983).

Even so, these efforts fail to inform us about maladaptation in family process. Only parents are consulted. Family strengths are ignored. Transactions are never measured. One is assured that some proportion of sample family members (that is, parents) manifest stress reactions. But on balance, the finding is not much different from those readily achievable with construct valid instruments.

#### 2.4 Success in Relation to Coping Attributes

On reviewing the stress-reaction research one discerns two inherent qualities which would have allowed it at least brief preeminence in the early family care literature. First, it always appealed to popular wisdom. In the minds of most, the parenting of a mentally retarded child implies an exceptional experience, one marked by a more than ordinary share of rigors. Second, so long as

the units of analysis were simpler than 'family', it consistently yielded defensible findings. Virtually every study which ever designated child characteristics and parent-reported stress as independent and dependent variables, respectively, seemed capable of producing a regression line.

And yet, these qualities were inadequate to ensure its endurance. Elsewhere, allied research communities were discarding unidirectional, causal models altogether, and instead were exploring the more dynamic constructs of family process and ecology. Family research in general was, towards the last decade, evolving into a formal science of system adaptability, focussing on the interplay between stress appraisal and complex problem-solving strategies. In none of its subdisciplines could stress reaction models remain impervious to criticism.

As such, in the mental retardation field it became increasingly evident that traditional paradigms were failing at the task they were intended for--namely, of explaining why it was that certain families were successful at home care while others were not. A substantial knowledge base had accumulated. But to many it was now seeming little more than an elaborate restatement of the original problem; home care was stressful, very stressful for some, less so for others.

Also evident, albeit subtly, was that correction of this failing would entail much more than a consideration of a few, simple mediating variables. Students of the family were arguing that these variables were immensely complex, and many, and that

their relations, in the structure of families of mentally retarded children, were as yet unknown. The argument portended an important shift in the direction of research, one whose earliest advocacy appeared in the work of Louis Rowitz. In a review of mostly sociological contributions, Rowitz (1974) contended that the family should become the first, and pivotal object of interest for all future psychosocial studies of mental retardation. No substantive innovation in knowledge could obtain, he suggested, until much more had been learned, both about the nature of coping, and the relationship between family and extrafamilial systems.

The thesis is interesting, when one considers that it remained essentially unmodified to the present. As it happened, neither of those two processes were operationalized very well until recent years, notably, in modern accounts of coping (cf. Murphy 1974; White 1974; Folkman, Schaefer, and Lazarus 1979), Bronfenbrenner's (1977) delineation of concentric, social contexts, and ecological, family research in general. Armed with this work, succeeding theorists reiterated Rowitz' conviction (Crnic, Friedrich, and Greenberg 1983; Kazak 1986). The interim was still brief, of course. And because of this little empirical work has been done. Such as that work is, however, it does tend to support Rowitz' arguments. One notices, on overview, that findings become more useful as both the accounts of transactions enrich, and units of analysis shift from the simple to the complex.

Being fairly new, the contributions to this literature

are not as yet formally unified by common theoretical traditions. Accordingly, the admittedly subjective decision has been made here to use the model of coping offered by Folkman and Lazarus (1980) as a kind of theoretical backdrop for the studies. Though subjective, the decision is not entirely arbitrary. For the most part the model is compatible with general systems theory. And as Crnic, Friedrich, and Greenberg (*ibid.*) have pointed out, the authors' catalogue of coping resources seems to fit well with the constructs so far investigated in the families of interest.

Very briefly, the model presupposes a relationship of "...ongoing...reciprocal action" (223) between person and environment, mediated by the processes of appraisal and coping. Appraisal, in this case, refers to the valuation of events, in which both the potential for harm or challenge, and range of available resources and options, are considered. The relevant resources are health/energy/morale/, problem solving skills, social networks, utilitarian resources, and general and specific beliefs (see Folkman, Schaefer, and Lazarus 1979). Coping is described as the employment of these resources in events, and said to serve either of the functions "management or alteration of the person-environment relationship that is the source of stress (problem-focussed coping)" or "regulation of stressful emotions (emotion-focussed coping)" (1980:223).

The model recognizes that coping efforts affect both subjective appraisals of events and their objective conditions. Thus, coping and appraisal are mutually influencing; and 'coping

process' is labile by definition, consisting of "what the person actually thinks and does in a particular encounter, and...changes in these efforts as the encounter unfolds during a single episode or across episodes...(224).

Predictably, one finds that most studies of coping and home care are framed by far less transactional models than Folkman's. Some, in fact, provide only minor variations on the stress-reaction literature, maintaining that the event of a mentally retarded child's birth in itself incites a fixed set of parental (or dyadic) responses. Ricci (1970), for example, argues that mothers of mentally retarded children are unusually rejecting and authoritarian in their parenting practices (cf. Cummings' et al. *ibid.* report on mothers' psychological states). Buckhalt, Rutherford, and Goldberg (1978) argue that parents of Downs syndrome children exhibit peculiar language training practices, and that these exacerbate delayed language acquisition in children. (Presumptively, in both cases we are witnessing maladaptive coping efforts.)

Stoneman, Brody, and Abbott (1983) use a unidirectional model to investigate the qualities of parent-child interactions. In dyads including Downs syndrome infants, parents were said to typically assume the dominant, teacher/manager role. "Clear role asymmetries" were the norm, joint play activities rare (598). Both fathers and mothers were also described as "extremely contingently responsive", a phenomenon the authors attributed to Downs

children's "limited behaviour repertoires" (ibid.). In sum, the constructs of interest were severely limited; and for the most part children were considered nonparticipants in family process.

A slightly more complex model orients the work of Bradley and Caldwell (1977;1979). Interested in the relationship between home environment and child, mental development, the authors offered the HOME inventory, an in-home observation measure which tapped both physical characteristics of family environment, and a host of parent behaviours. In the instrument family resources (scored items) roughly correspond to utilitarian and problem solving categories--subscales include "characteristics of the family home" and "modeling and encouragement of social maturity". I.Q. of the child is the criterion of successful, family functioning.

Bradley's and Caldwell's studies were largely intended to yield an effective screening device, a means of identifying children at risk of psychosocial retardation. However, the implicit model is historically interesting. It was presupposed that family resources would interact prominently with child characteristics (inherent risk factors) to influence child development. The model presumes a largely unidirectional causality. But at the same time, parent characteristics were treated as independent variables, and comprised social, behavioural competencies, rather than thoughts and mood states.

Their findings were encouraging. HOME scores

consistently correlated with intelligence measures. Better yet, HOME proved useful at predicting changes in I.Q. test performance in Downs children (Piper and Ramsay 1980). The measure seemed to have intriguing possibilities for family assessment and intervention, and still does. Of course, in the research there has remained the temptation to employ it within a strict, stress reaction format. Affleck et al. (1982), for example, argued that infant characteristics influence maternal self-reported stress and depression, and that HOME scores covary in turn.

The greater concern, however, is that the HOME's predictive power seems to be quite uneven across homogeneous groups (see Adam's, Campbell, and Ramey 1984). So far, observed differences have not been so great as to warrant dismissing the HOME research. Rather, since the constructs it measures may have variable importance to child development from setting to setting, the most appropriate use of the scale may be as a corroborative measure in more ecological, and multivariate investigations.

The remaining work on coping and home care is fairly eclectic, in the the assignment of both independent variables and success criteria. However, among many of the studies one sees a common commitment to a kind of premorbid coping/postmorbid adjustment model, one in which coping process is agreed to be only mediated, rather than directly induced, by the presence of a handicapped child. Zuk et al. (1961) report that certain religious backgrounds correlate positively with maternal acceptance of

retarded children. Most important, it is argued, is the extent to which faith mitigates parents' feelings of personal guilt for their children's handicap.

Using Holroyd's QRS as a general success, or "coping ability", measure, Friedrich (1979) argues that among mothers of handicapped children marital satisfaction is the best overall predictor variable, followed by social support and psychological well being. (Interestingly, in this single-interview study a multiple regression analysis revealed that severity of child disability was not a predictor at all.)

Equating ability to cope with longevity of home placement, Sanderson and Crawley (1982) describe successful family-care parents as generally older, and more active in churches than their unsuccessful counterparts.

The studies provide clues around the causation of success, but being synchronic are largely unable to illuminate coping process. Future research may be guided by Nihira's et al. (1983) studies of home environment and development of mentally retarded adolescents. Briefly, the authors corroborated earlier research done with HOME measures. But in addition, they showed that while a fairly wide spectrum of environmental variables influenced child development generally, the effects of children on parents were comparatively specific. As child I.Q. increased, for example, parents were reinforced to stimulate academic behaviour. Similarly, child 'psychosocial adjustment' tended to have a direct bearing on parents' demonstrations of physical punishment, pride,



and affection.

## 2.5 Social Networks and Social Support

One broad, coping attribute which has received considerable attention in recent years is social support. Following on the landmark work of Cassel (1976) and Cobb (1976), a wealth of literature now describes the importance of social networks and social support as buffers against the pernicious impact of stress (cf. Croog, Lipson, and Levine 1972; Lin et al. 1978; Kessler et al. 1985). Elements of social support receiving greatest attention within the clinical literature include structural characteristics of networks, types of support or support content, support mobilization, and satisfaction with support (see Gottlieb 1981; Saulnier 1982; Tardy 1985).

While some clinical research explores the impact of a few aspects of support and support networks on mixed populations, it has become increasingly popular to examine a wide array of variables at once in selected groups. Most such studies are exploratory, and argue that the importance of social networks can only be understood in relation to the distinguishing traits and needs of their members. Thus we see studies examining the role of networks in such diverse experiences as poverty in urban settings (Stack 1974, 1980), the transition to parenthood (Duvall 1971), chronic illness (Coulton 1979), and marital disruption (Wilcox 1981).

Within this tradition, a small body of research has focussed on the role of support and support networks in the process of adapting to home-care of disabled children. Bregman (1980) lived briefly with six families with children suffering muscular dystrophy or infantile spinal muscular atrophy. The narrowest object of interest was gross coping process. Data were qualitative, but each of the case accounts highlighted the importance of network mobilization as an adaptive strategy.

Not surprisingly, all families kept contact with other families with disabled children, sharing respite and providing vital information on care-related issues. Equally important, however, were longtime friends and family members. In many areas, it was noticed, families would go to lengths to preserve normalcy in their social lives, as if to prevent needless, negative changes which might result from the birth of a disabled child. Often, supportive contacts provided respite. But equally important, it seemed, were recreation, information, and opportunities to ventilate on the stresses of caregiving. (Venters 1981 made similar observations of families with children suffering Cystic Fibrosis.)

Friedrich et al. (1985) used standard measures (including Holroyd's QRS) to examine the relationship between four, broad categories of coping resources, including social support, and parent reported stress in families with mentally retarded children. A multiple regression framework was employed. Using 'medical involvement of the child' and 'child behaviour

problems' as independent variables, support availability and perceived support each time contributed heavily to the final regression statement.

Crnic et al. (1983) examined the relationships between social support, stress, life satisfaction, and mother-infant interactions in a study of mothers with premature infants. Again, support seemed to have important buffering effects; but in this case they seemed fairly specific. Perceived social support from intimate ties and contacts within the community each seemed to have a moderating effect on stress, and were associated with higher, general life satisfaction. Interestingly, though, this did not occur with perceived support from friends. Further, only perceived support from intimate contacts seemed to have a positive impact on mothers' affect in interactions with their infants.

In a study of mothers of developmentally delayed children, McKinney and Peterson (1987) made somewhat corroborative findings. Using a measure which recorded perceived support from four persons other than one's spouse or children, the authors found no relationship between perceived support and stress.

By far the most rigorous research in this area appears in the work of Kazak and Wilcox (1984) and Kazak and Marvin (1984). Briefly, the authors assessed social support in families with children having spina bifida and matched, comparison families. Clear differences emerged in that the former seemed to have unusually small, dense networks, and a significantly greater

reliance on multidimensional (multifunctioning) contacts. A traditional analysis would take this as evidence of social isolation (cf. Suelzle and Keenan 1981). However the authors in this case argue that a kind of positive-functioned enmeshment takes place, such that faced with the unlikelihood of sustaining casual ties the family creates elaborate linkages with a relative small number of supportive contacts.

While the pattern is described as an adaptive response to an exceptional life circumstance, some negative artifacts are described as well. The authors noticed an inordinate specialization in the parental subsystem. Moreover, it is suggested that the lack of 'weak links', particularly in the friendship network, may act as a barrier against novel advice and information.

Later, Kazak (1987) corroborated these findings, in a study involving four groups of families, one having children with no disabilities, the remaining groups each representing a child with a particular type of disability. Interestingly, while differences between families with disabled children and those without were few, support networks differed substantially across the three groups with disabled children (particularly in parents' network size and density). The finding supports Kazak's earlier suggestion that the caregiving demands inherent in parenting a disabled child place unusual stresses on the friendship network, in particular, but opens new questions as to the effects of particular disabilities on support network organization.

The work of Kazak's and others represents an immensely valuable contribution to the family literature. But it also reflects a fairly new focus in family research. As such, there continue to be great gaps in our understanding as to which elements of social support and support networks facilitate families' adjustment to the care of a disabled child, and which such elements are neutral, or largely negative in their implications.

Chapter Three  
Practicum Organization  
and Study Plan

3.1 Parameters of the Practicum

3.1.1 Practicum Site/Sponsorship

The study was overseen by the Child and Family Services Research Group, a nonprofit independent research organization attached to the University of Manitoba Faculty of Social Work. The C.F.S.R.G. serves as centre of research activities for faculty members and students of the Department. However, the group is also substantially active in interdisciplinary work and cooperative research undertakings between the University, community groups and agencies, and government. Its stated objectives are "...to promote Child and Family Services research that is relevant to social work practitioners and to the academic community, to work cooperatively on interdisciplinary and interprovincial levels to develop innovative approaches to research, and to institute a dissemination strategy to maximize the distribution and use of knowledge gained through research." (C.F.S.R.G. 1989:4)

Two public agencies provided assistance to the study. One was the Child Development Clinic (C.D.C.). Based in the Health Sciences Centre, an inner city teaching hospital, the clinic serves as the province's central diagnostic and testing facility for children with developmental delay. Virtually every infant in

the province observed by a guardian or physician to be potentially delayed will be referred to the clinic for diagnosis and follow-up examination.

The second was the Children's Special Services (C.S.S.) Branch of the provincial Department of Community Services (now Manitoba Family Services). C.S.S. serves as the province's responsibility centre for funding, standards monitoring, and program development relating to services to children with nonpsychiatric disabilities. The functions of the Branch are largely administrative. However, one employee, a social worker, provides a wide range of counselling, information, and referral services to families with children being seen by the Child Development Centre.

### 3.1.2 Practicum Committee and Process of Supervision

The practicum examining committee was assembled prior to the study's design and implementation. The committee's external member was Mr. Sid Frankel, Senior Policy Analyst, Research and Planning Branch, Manitoba Community services. Mr. Frankel was invited to the committee for his expertise in human service evaluation and quantitative research methodology. As a planner in Community Services, Mr. Frankel also brought substantial working knowledge of the programs and service-related issues of the Children's Special Services Branch. Dr. Don Fuchs, Associate Professor, University of Manitoba Faculty of Social Work, was the second member of the committee. As a member of C.F.S.R.G., Dr.

Fuchs brought expertise in evaluative research in Child and Family Services, and, particularly germane to the present study, in the analysis of social networks and social support.

The principle examiner was Dr. Barry Trute, Professor, University of Manitoba Faculty of Social Work, and Director of the C.F.S.R.G. As Director of the larger study, Dr. Trute had lead responsibility for the project's design and implementation. Dr. Trute made initial contact with the various participating agency and government representatives, represented the study in the authoring of its terms of reference, and oversaw the activities of the two students.

Students had a wide latitude to review the relevant literature, prepare the measures which would capture the constructs of interest to the practica, and contribute to the study's design and implementation process. In two meetings with the full committee, the overall design of the study was discussed, and refined. In these, and subsequent meetings involving the principle examiner and students, research relating to family care of developmentally disabled children was shared and discussed, issues around instrumentation were resolved, and the design and procedures of the study were reviewed in detail.

Much of the discussion at this stage centred on the task of ensuring that the final survey would be both fluid and coherent in its reading, as well as relevant to the general requirements of the study itself. An omnibus survey was prepared, to capture a wide range of respondents' perceptions on their social world. With



so broad a focus the survey quickly grew in length, and thus it became a challenge to do editing, in such a way as would not compromise the survey's global character. With so many measures used, ordering became an issue. In the end, it was decided to sequence measures such that to the greatest extent possible smaller social systems would be addressed prior to larger ones, and questions having greatest reactive potential would be left towards the end.

A first draft of the measure was then pretested. Students administered the study to one another, to friends and family members, and finally to a sample of parents of young children with physical disabilities. At junctures throughout the pretesting period, the students met with the project coordinator to discuss areas in which the measure required modification. Of particular importance was item clarity, in those scales which had been designed for the study, negative reactions to questionnaires requesting personal information, and problems relating to the length of the measure.

By the time pretesting was done with parents of disabled children, the measure was essentially in final draft. With minor modifications introduced, interviews with the study's sample families began. Throughout the interview period, the research team met regularly to discuss issues arising out the research process. Following implementation, students consulted with the coordinator on statistical analysis, and initial statistical reports were reviewed.

### 3.2 Study Parameters

#### 3.2.1 Subjects

Families were referred to the study from the Child Development Clinic. The C.S.S. coordinating social worker was directed to consider all families who the clinic had served within the last three years, and identify a sample comprising families which could be said to be functioning well, following the birth of their developmentally delayed child. Three, broad criteria were applied to selection: 1) The child receiving services was ostensibly happy, and coping well within the family context, 2) The family was well adjusted in the circumstance of supporting the child at home, and 3) The child was performing within acceptable, developmental parameters. Following initial selection, a pool was created, consisting of a sample of 40 well adjusted families and a like-sized, random cross-section of other families seen at the centre.

Staff pediatricians who had been kept blind to the selection process were then asked to discern which group each family had initially belonged to. With an inter-rater consistency of 91%, the original sample was contacted. (Interestingly, agreement was reached in the case of three families who failed to satisfy one element of the first criterion. In these cases, severity of child disability precluded judgement as to the child's emotional state.)

All but four of the families participated; three were inaccessible, and one refused. Semi-structured interviews were

thus conducted with 36 families, each done in a family's home. (3 data sets were incomplete, owing to fathers' being unavailable during the research period.)

### 3.2.2 Measures

Both mothers and fathers were asked to independently generate a list of all those they regarded as supportive friends or family members. No ceiling was imposed on number; instead, respondents were asked to cite all those they would feel comfortable contacting, for any purpose, in the event of personal or family-related difficulties, or at times of stress in general. The procedure enabled calculation of respective network size, and spousal boundary density (proportion of overlap in membership; Kazak and Wilcox *ibid.*).

A questionnaire designed for the study appended the list supplied by mothers. Mothers noted the sex of each contact cited, as well as relationship (in the case of family) and length of relationship. Frequency of contact was recorded by way of a five point, Likert-style scale, with endpoints of "once a day" and "less than once a month". In addition, mothers were asked to note the type of support they received from each network member according to the response categories: emotional support, material aid support, advice and information, physical assistance, social participation, and respite. (The first five of these comprise the full range of response categories used in Oritt's et al. 1985 PSNI; respondents received the original narrative descriptions

which accompany that scale.) In customary fashion, the dimensionality of each contact cited was calculated as the sum of support types she or he was said to provide.

Network density (proportion of contacts who maintain association with one another independently of the respondent) was determined by the use of a conventional, social network density grid (see Kazak and Wilcox *ibid.*).

Mothers also completed three standard measures. The first, McCubbin's et al. (1982) F-COPES, is a global measure of family coping style. Two subscales are considered in the present study--"Acquiring Social Support", a measure of a "family's ability to actively engage in acquiring support from relatives, friends, neighbours, and extended family" and "Mobilizing Family to Acquire and Accept Help", which captures families' ability to seek out and accept support from community resources (104). Validity estimates are not as yet available. However, each subscale has shown an acceptable degree of internal consistency (Acquiring Support:  $\alpha = .83$ ; Mobilizing Family:  $\alpha = .71$ ) and test-retest reliability (each at  $r = .78$ : four week interval).

The family subscale of Procidano's and Heller's (1983) Perceived Social Support from Families and Friends (PSS) was also provided. The PSS-Fa is a 20 item measure of the degree to which respondents believe that their needs for "support, information, and feedback are fulfilled by family" (2). Most items focus on support reciprocity, although a few items do test for support provision, thereby correcting for asymmetrical relationships with

supportive contacts. The scale seems fairly homogeneous ( $\alpha = .90$ ) and stable over time (test-retest  $r = .83$ : four week interval). Validity of the measures has been established in a variety of ways, in three studies by the authors (ibid.) involving standard, self-report measures, mood induction techniques, and actual observations of interactions between respondents and cited contacts.

Finally, mothers completed a short-form (random half) of the Marlowe Crowne Social Desirability (SD) (Crowne and Marlowe 1964).

Parents jointly supplied family demographic data, and information pertaining to child disability. Two scales designed for the study captured the latter (These were prepared by the project's coordinator, not the author). The first requested specification of the disability, and details regarding attendant symptoms (hearing loss, vision loss, hyperkineticism, and so on). The second was a four item, Likert-styled Disability Index which asked parents to predict the disabilities' impact in terms of long-term physical management and medical needs, and intellectual development ( $\alpha = .80$ ).

### 3.2.3 Procedures

As mentioned, pretesting of the larger questionnaire was done in three stages. First, in turns the three interviewers involved in the project (2 students, and one volunteer) administered surveys to one another; this allowed for discussions

on interview process and item clarity. Next, interviewers surveyed a small sample of (ten to twelve) friends and relatives. Finally, with minor modifications of certain scale items introduced, six parents of young children with physical disabilities were interviewed. Using their comments, the final instrument was prepared.

In the interim, staff of the Child Development Clinic derived the study's initial sample. Families received covering letters explaining the study, each signed by the C.D.C. coordinating social worker and the director of Children's Special Services. The names of those who participated in the study were then passed on to the research team.

Members of the team then contacted families by telephone. It was explained that interviews would take upwards of one and one half to two hours to complete, with fathers being involved during roughly the first half, and mothers for the full duration. Additional background on the study, and an overview description of the interview's content and process, was provided. Reimbursement was offered for any child care expenses which might be incurred as a result of the interview.

At this stage, prior to the interviews themselves, provisions relating to confidentiality were emphasized. All respondents were assured that no one outside the research team would have access to the surveys, and that prepared text would never provide enough information to allow any reader to relate responses to individual respondents. Further, all families were

advised that while they had agreed to participate in the study, they were free to withdraw at any time. No one outside the research team--most importantly, no one in a position to influence service provision to the families--would know who had fully participated and who had not.

## Chapter Four

### Research Results

#### 4.1 Introduction

In the sections which follow, basic demographic and disability-related data are presented. Findings concerning social support networks are reported in two general formats. In one, structural characteristics of networks and standard measure scores are outlined in aggregate form only. Since the central intent of the study was to report modal traits of what was assumed would be a fairly homogeneous group, within-group analysis of the experimental sample was avoided. A separate subsection examines the sample derived by the families themselves--the supportive contacts.

Some of the findings outlined in this chapter have appeared in a report to the Province of Manitoba (as stipulated in the terms of the project: Trute, Hauch, and Marginet 1986), and two research papers (Trute and Hauch 1988a,b)

#### 4.2 The Children and their Families

The mean age of children included in the study was 3 (SD = 3). 23 of the 36 (64%) were males. (Apparently, this high proportion of males is not unique to successful families. Sex was similarly distributed throughout the sample frame.) Ten (28%) were



only children. Of those who had siblings, 6 (17%) were the eldest or elder child. Many were the second of two children (36%,  $n = 13$ ). A sizable proportion had been diagnosed as Down's Syndrome (36%,  $n = 13$ ). The remainder presented an array of handicapping conditions, whose most prominent outcome was developmental delay.

Parents' reportage on the Disability Index varied, and as it turned out failed to depict a predominantly mildly handicapped sample. Mental or intellectual development was said to be severely compromised in the case of 20% of the children; severe physical impairment was predicted for 10%. 10% of the children were described as being in extreme need of ongoing, specialized medical attention. And 18% were said to be likely to require constant assistance, over the years, with such everyday activities as eating, bathing, and toileting.

All but one of the families contained two coresident spouses, each being the consanguinal parent of the disabled child. (One family was headed by a single mother.) Parents' ages varied (mothers mean age = 32,  $SD = 7$ ; fathers mean age = 35,  $SD = 8$ ). However, there was a strong correlation between spouses' ages ( $r = .92$ ,  $n = 35$ ,  $p < .001$ ), showing that the typical age difference between spouses was quite small.

Of the mothers, 44% had studied beyond high school. And yet, many (54%) described themselves as full-time homemakers; only 11% reported being employed full-time outside the home. 60% of the fathers had continued their education beyond high school, and 91% were employed full-time outside the home. Taxable family income

was distributed throughout major income categories. Thus the sample included families who were arguably poor, by national standards, as well as those who enjoyed average and above average incomes.

#### 4.3 Network Characteristics, Perceived Support, and Support Mobilization

Sex of spouse seemed to be a poor predictor of network size. Table I illustrates; comparisons of means for network size showed no significant differences (mean size of mothers' networks in the present study = 7.47, SD = 2.81; of fathers = 6.84, SD = 4.01;  $t = 1.80$ ; n.s.: two-tailed probability).

. Both mothers and fathers networks would seem objectively small, however. In Kazak's and Wilcox' (1984) study, noted earlier, parents in "comparison" families (families with no handicapped members) were reported to have a larger number of supportive contacts than was found for parents in the present study. Such was particularly the case for mothers (mean size of mothers' networks in the present study = 7.47, SD = 2.81; of "comparison" mothers = 11.2, SD = 4.7;  $t = 4.22$ ,  $p < .001$ ).

Table I. Means and Standard Deviations for Network Size

	Mothers' (n = 36)	Fathers' (n = 32)
Total network	M = 7.47 S = 2.81	M = 6.84 S = 4.01
Family Network	M = 4.33 S = 1.85	M = 4.03 S = 2.29
Friendship Network	M = 3.14 S = 1.69	M = 2.81 S = 2.32

Not surprisingly, mothers' networks tended to be composed largely of other women. When total networks were examined, the average ratio of female to male members was 2.93/1. This figure was most heavily influenced by friendship networks, 27 of which were discovered to be exclusively female. However, a high female/male ratio was also evidenced in family networks (1.51 to 1 on average). Mothers seemed to be more likely to turn to female family members than male in times of crisis, a pattern which apparently subordinated preferential reliance on family of origin. For example, while 15 sisters-in-law were cited as supportive contacts, only 5 brothers were.

In addition to being largely female in membership, support networks were also highly versatile in their provision of support. Table II shows that mothers tended to have at least one, and often more than one, person providing each of the recorded support types. Given the small size of networks, of course, this could only be accomplished by a high prevalence of

multidimensional contacts. Family members provided an average of 3.45 support types (SD = 1.82); friends, 2.93 types (SD = 1.52) (Notably, while friendship contacts were surprisingly multidimensional, family contacts were significantly more so;  $t = 2.55$ ,  $p < .01$ ).

Table II. Mean number of Friends and Family Providing Various Types of Support to Mothers

Type of Support	Number of Family Contacts Providing	Number of Friendship Contacts Providing
Emotional Support	mean = 3.41 s.d. = 1.55	mean = 2.63 s.d. = 1.94
Material Aid	mean = 1.88 s.d. = 1.83	mean = 0.58 s.d. = 1.02
Advice and Information	mean = 2.47 s.d. = 1.92	mean = 1.94 s.d. = 1.63
Physical Assistance	mean = 2.19 s.d. = 1.60	mean = 1.38 s.d. = 1.42
Social Participation	mean = 1.63 s.d. = 1.75	mean = 1.41 s.d. = 1.68
Respite	mean = 2.36 s.d. = 1.75	mean = 1.11 s.d. = 1.41

Some of the most interesting findings concerned network density and boundary density. Kazak and Wilcox (1984) had earlier shown that the support networks of families with handicapped children were typically very dense--that is, members had an unusually high likelihood of knowing and interacting with one another. Looking at Table III, one sees that this is also the case with successfully adapted families. However, for this group the effect is apparently selective. Total network density is higher than one finds in families without a handicapped member. But density in the friendship network is not. What seems, then, to distinguish the present successful families from families with children with spina bifida is their ability to maintain a loosely knit constellation of friendship ties.

Table III. Means and Standard Deviations for Mothers' Network Density, with Comparisons with Findings from Kazak and Wilcox (1984)

	The present study sample (successful families (n = 36)	Kazak and Wilcox	
		spina bifida families (n = 56)	comparison families (n = 53)
Total network	M = 69.19 S = 20.27	M = 69.70 S = 24.20	M = 56.90 S = 25.30 <sup>a</sup>
Family Network	M = 95.41 S = 12.48	M = 95.70 S = 10.50	M = 91.20 S = 17.20 <sup>b</sup>
Friendship Network	M = 40.56 S = 35.92	M = 57.70 S = 33.50	M = 43.20 S = 30.10 <sup>c</sup>

<sup>a</sup> Network density of comparison families was significantly lower than that of both the present and spina bifida families.

<sup>b</sup> No differences were found to exist between the groups.

<sup>c</sup> Network density of spina bifida families was significantly higher than that of both the present and comparison families.

[In a,b,and c above, t-tests used  $p < .05$  to test for significant differences; two-tailed probability]

Boundary density, or degree of overlap in (in this instance) spousal networks was also typically high in the present sample. The effect was especially pronounced when family networks alone were considered. Reviewing Table IV., one sees that in the present sample spousal boundary density in the family subnetwork is substantially higher than that in the other two groups considered (families with no handicapped member and families with children with spina bifida).

Table IV. Means and Standard Deviations for Network Boundary Density, with Comparisons with Findings from Kazak and Wilcox (1984)

	The present study sample (successful families (n = 36)	Kazak and Wilcox	
		spina bifida families (n = 56)	comparison families (n = 53)
Total network	M = 30.31 S = 24.72	M = 20.70 S = 25.10	M = 11.30 S = 9.10 <sup>a</sup>
Family Network	M = 46.41 S = 31.33	M = 28.60 S = 32.50	M = 16.80 S = 18.80 <sup>b</sup>
Friendship Network	M = 10.25 S = 18.44	M = 10.40 S = 22.70	M = 22.70 S = 9.30 <sup>c</sup>

- <sup>a</sup> Network boundary density of both the present and spina bifida families was significantly greater than that of comparison families.
- <sup>b</sup> Network boundary density of the present families was significantly greater than that of both spina bifida and comparison families.
- <sup>c</sup> No differences were found to exist between the groups.

[In a,b,and c above, t-tests used  $p < .05$  to test for significant differences; two-tailed probability]

That these families are ostensibly successful would suggest that this trait may have selective advantage. The speculation is supported by mothers' scores on measures of satisfaction with support from family. PSS-Fa scores were significantly higher than scale construction norms (study PSS-Fa mean = 16.6, SD = 3.66; norm mean = 13.4, SD = 4.83;  $t = 3.37$ ,  $p < .001$ ). Accordingly, only a small number of supportive contacts were reported by the mothers to "block change...make them uncomfortable...or influence them negatively". Five of the mothers

cited a total of 10 such contacts (4 mothers, 2 sisters, 2 friends, 1 father, and 1 mother-in-law). All five of the mothers scored below the PSS-Fa scale construction mean.

There is also reason to suspect that the unique features of these networks are not fortuitous in origin, but instead are the outcomes of actual productive effort on the part of family members. As it turned out, mothers surveyed also scored significantly higher than scale construction norms on both of the F-COPES subscales considered in the present study. (study mean for Acquiring Social Support = 33.1, SD = 5.2; norm mean = 27.8, SD = 6.5;  $Z(x) = 4.88$ ,  $p < .001$ ; study mean for Mobilizing Family to Acquire and Accept Help = 15.3, SD = 3.1; norm mean = 12.7, SD = 3.3;  $Z(x) = 4.73$ ,  $p < .001$ ).

None of the scale scores noted in the foregoing, including those describing structural features of social networks, correlated with Social Desirability measures.

#### 4.4 Trends Observed in the Sample of Cited Contacts

Among mothers, 113 friendship contacts were cited, and 155 family. As mentioned, family contacts were more likely to be female than male, and accordingly spouses' family members were more than amply represented. Most friendship contacts were fairly longstanding. Only 18.6% of friendships had been formed within the previous 2.9 years. 28.3% of the friendships were of 3 - 5.9 years' duration; 16.8%, 6 - 8.9 years. And 36.3% had been respondents' friends for 9 years or more.



Analysis of support type data by the categories friend/family yielded interesting, if somewhat limited, results. As family members tended to be more dimensional than friends in support provision, it was inevitable that a significantly greater proportion of family than friends would be found to provide one or more of the support types mentioned. Such held true in the case of material aid, physical assistance, and respite. Unfortunately, however, the present measures failed to capture perceived magnitude of support provision. Thus, the fact that friends were not reportedly superior to family in the provision of any one type probably belied their true importance to respondents. As it was, friends seemed most frequently to be sought out for emotional support, advice and information, and social participation.

Table V. Percentage of Friends and Family Providing Various Types of Support to Mothers

Type of Support	% of Family Providing	% of Friends Providing	Adjusted Chi-sqaure	sig.
Emotional Support	81.3	85.0	0.38	n.s.
Material Aid	47.1	17.7	23.64	.001
Advice and Information	59.4	64.6	0.55	n.s.
Physical Assistance	55.5	41.6	4.50	.05
Social Participation	42.6	51.3	1.67	n.s.
Respite	59.4	32.7	17.48	.001

Analysis of frequency of contact data suggested that respondents maintained fairly regular contact with most network members. Of 268 contacts cited, fully 78% were described as having at least biweekly contact with a respondent. As expected, frequency of contact with family was somewhat greater than that with friends (see table VI). Interestingly, though, the effect disappeared when only female contacts were considered (ie., when analysis ignored the "daily" contact with husbands). Thus, friends clearly figured prominently in the pattern of daily life.

Table VI. Number of Friends and Family Cited in each of Five Frequency of Contact Categories

	Daily	Weekly	Every 2 weeks	Monthly	Less than monthly	Row Total
Friends	20	39	20	22	12	113
Family	56	55	18	13	13	155
Column Total	76	94	38	35	25	268

Chi-Square = 16.05,  $p < .01$

Network members having the most frequent contact with respondents were likely to be among the most dimensional support providers. When all contacts were considered frequency of contact showed a strong, positive association with support dimensionality (Kendall's Tau C = .357,  $p < .001$ ). The relationship was equally strong when friends and family members were considered separately (Friends: Kendall's Tau C = .328,  $p < .001$ ; Family: Kendall's Tau C = .356,  $p < .001$ ).

## Chapter Five

### Discussion and Conclusions

#### 5.1 Introduction

As mentioned, the present study, while having the general requirement to yield defensible findings, was first of all mandated to provide an experience in applied research. One can appreciate that this poses certain challenges to the discussion of findings, since from the student's point of view what is found, so to speak, derives as much from research process as data, if not more so.

Section 5.2, then, provides a discussion on the actual findings of the study itself. Section 5.3 describes areas of the student's learning, as they relate to the implementation of applied, family research in a human service setting. Section 5.4 discusses areas of learning specifically having to do with the measurement and analysis of social networks and social support.

#### 5.2 Discussion of Research Findings Relating to Social Network Attributes of Well Adjusted Families

As survey data were reviewed, recurring themes in the nature of successful families' networks emerged. Most conspicuous was that the number of supportive contacts tended to be quite small. This finding was consistent with previous research, and conventional wisdom, which argues that home care of a disabled child implies at least some degree of social isolation on the part

of principal caregivers, success notwithstanding.

At the same time, however, there was no complementing evidence to suggest that the sum of support itself was modest, or that the families enjoyed only marginal freedom in determining the composition and function of supportive networks. Quite the contrary. For a start, almost without exception mothers stated that the majority of their closest contacts were other women. Many of these were longtime friends. But some were new friends; and quite a few were new family--close affiliations established with husbands' mothers and sisters. Most mothers, in fact, reported having established close contacts shortly prior or subsequent to the birth of the child. Thus, in the present sample it could clearly not be said that a gradual distancing from friends and family had occurred.

In addition, the support itself seemed neither limited in type nor infrequently extended. In the majority of cases, successful families were the recipients of all manner of support types. And the families were apparently able to maintain regular contact with most support providers--most regular, in fact, with those persons providing the greatest variety of support.

Successful families' networks were thus typically small, and abundant in support provision. But beyond that, the structures seemed to be accommodating important specializations. Mothers' mean total network density, for example, was high--a not unusual finding in families providing sole care for handicapped children. However, mean density of friendship networks was quite low.

The finding is an intriguing one. On the one hand, the sheer logistics of caring for a substantially disabled child at home would seem to militate against the this kind of structure. The demands of parenting in such circumstances are considerable; and thus opportunities to make casual friendships, and maintain association with an array of persons not known to one another must be few. On the other hand, though, loosely knit friendship networks have been associated with positive adjustment to events requiring substantial life change (see Wilcox 1981). Explanations for this are various, but most emphasize the role which casual contacts play in providing novel advice and information. By extension, in their study noted earlier Kazak and Marvin (ibid.) report an inverse relationship between parents' network density and self-reported stress, thus showing that a high degree of enmeshment in networks may actually be maladaptive for families with handicapped children at home.

It seems reasonable to suggest, then, that low density in friendship networks provides an advantage to families with a handicapped child at home, and furthermore that this trait is only achievable by directed effort. Kazak's research suggests that the natural tendency is for families to witness progressive enmeshment in friendship networks from the point of the child's birth onward. In contrast, the families interviewed for the present study described structures which in this dimension were fairly similar to those of families with nonhandicapped children.

A second, apparently identifying feature of successful

families was unusually high spousal boundary density in both total and family networks. The finding is difficult to interpret. Kazak has suggested that high boundary density evolves from the same factors which lead to small network size; that is, the casual ties kept separately by each spouse may be vulnerable to neglect, as caregiving demands force social networks to become smaller. On the face of it the argument seems reasonable. But it is interesting that the phenomenon is exaggerated in the case of successful families. When comparisons were made to Kazak's and Wilcox' (1984) findings (see Table IV.) spousal boundary density of successful families was found to be significantly greater than that of a random sample of families caring for children with spina bifida. This is not something we would expect if high boundary density was primarily an outcome of social isolation.

Most mothers reported having frequent contact with family and friends. This suggests that high spousal boundary density is much more a product of mothers' free will than it is simple, unhappy fate. This is corroborated by mothers' scores on support acquisition and mobilization measures. Mothers are clearly playing a strong role in determining the architecture and membership of their supportive networks. High spousal boundary density may serve to strengthen the spousal subsystem. But other possibilities may exist as well. It may be that the cultivation of linkages with in-laws facilitates balance in relationships with persons whose everyday assistance mothers would require as a natural matter of course.

Within so focussed a study it is difficult to derive global recommendations for practice. It is noteworthy, however, that this sample of successful families was distinguished neither by high income nor minor degree of impairment in the disabled child. At this early stage, the research seems to suggest that characteristics of family functioning and organization play a far more prominent role in families' ability to adjust successfully to the birth of a developmentally delayed child.

This in itself should inform practice. A traditional view holds that the birth of a developmentally disabled child is an intrinsically negative life event, whose pernicious effects are determined by a combination of the nature and severity of the child's impairment, and personal attributes of coresident family members. In contrast to this view, the present study suggests that the birth of developmentally disabled child can be a largely positive event, as long as the family is broadly cable of responding adaptively to the circumstance. Workers in the field, therefore, should be at least as attuned to family coping style as to specific psychological effects on individual family members.

Much more could be learned about these findings in a cross sectional survey, where degree of family adjustment was assessed after the fact. As interesting would be a longitudinal study of successful families with disabled children. As it is, while it is possible to generate hypotheses on the ways in which supportive networks contribute to family strength, more needs to



be learned about the evolution of the structures described here. There is little question that the subject matter is worth the effort. To be sure, we know a very great deal about the consequences of failed parenting of disabled children. What is clearly needed now is for us to learn more from those families who are coping with the causes.

### 5.3 Practicum Outcomes: Research Process

#### 5.3.1 Maintaining Investment of Agency/Government Personnel

It was surprising to discover within the setting of a complex human service, a setting as much influenced by political process as the rules of the helping professions, that it was possible to implement a study whose findings could be generalized. To an important extent this was due to our having access to a sampling frame of high quality. In addition, the study was not designed as a conventional summative evaluation. The intent of the study was to provide broad, comparative case-styled data on the experiences and characteristics of a particular group, notwithstanding its involvements with any specific service provider. While respondents' experiences with the helping system were recorded, the actual impact of services was not measured. Thus the study had largely formative implications for the agency.

Beyond this, the skill of agency staff, their willingness to provide assistance to the study, and high quality of agency records all provided conditions favourable to the performance of applied research. It was safe to assume that the

success of the research project would depend on the degree of investment of various government officials and agency staff. At the outset, however, I was largely unaware of the general conditions upon which that investment would rest. Initially, I believed that a research project would only be accepted in the field if it could be shown that its findings might have direct and immediate application to service delivery. I believed that the project would need to provide products normally associated with management consultants, a systematic identification of problems in programming, for example, or the creation of a permanent management information system.

Instead, establishing working relationships in the field was much more a matter of maintaining simple goodwill. Being directly acquainted with the population of interest to the study, government staff were keenly interested in the study's more theoretical findings, as well as those focussing on the service system. Retaining their assistance, which for their part involved no minor inconvenience, was thus largely a matter of extending common courtesies. It was important, for example, to show an understanding of bureaucratic process, such as when delays resulted from the need to confirm certain official approvals. It was also important that the team show an understanding of Child Development Clinic and government policies. As an example, a complex protocol was devised to ensure that the sampling process would never violate agency regulations regarding client confidentiality.

Above all, the ability of the team and agency staff to function together on the study rested on clear mutual understandings as to the intent of the study, the scheduling and assignment of tasks, and ownership of data. Throughout the study there was never confusion as to workload issues. C.D.C. staff appreciated knowing at the outset precisely what their involvement would entail. And none of the activities of the research team was ever unannounced. Further, C.D.C. staff knew well in advance what questions would be asked of respondents, and how, and under what general conditions, findings would be disseminated.

Beyond these preparations, it greatly benefited the study's design to incorporate staff's trained judgments. Ongoing consultation enhanced the study's credibility, thereby preventing it from ever being viewed as an extraneous event in the agency. Most important, experienced field workers provided valuable advice on the design of certain of the study's measures--particularly those having to do with the local service system--and offered useful suggestions on interviewing.

### 5.3.2 Pretesting

The elaborate pretesting process was very instructive, both as a general educational exercise, and as an aid to the study itself. As discussed, pretesting was done in three stages: first within the team, then with an opportunistic sample of friends and families, and finally with young parents of disabled children.

The intent of the exercise was to screen for areas of

weakness in the questionnaire, and to provide students with an opportunity to practice administering the large measure. Pretesting focussed on three broad aspects of the survey. The first was size. The team agreed that the first draft omnibus measure was so lengthy that it had the potential for straining subjects' ability to provide considered responses. At the same time, though, there was very little in the literature to suggest which dimensions of family and extended social life might be comparatively unimportant to the success of parenting, in the sample in question. With the team not being willing to relinquish many of the measures, therefore, it became necessary to find time efficiencies.

The questionnaire was to be administered to both parents simultaneously. One large section, focussing on the families' experiences with the formal helping system and on the impact of the child on family life, actually required parents to pool their judgments, and provide a collaborated response. This gave interviewers a chance to experiment with various techniques of coordinating interviews. In the simulations respondents provided substantive feedback on interview process, in particular on the extent to which interviewers were able to focus them on their tasks and avoid highlighting obvious time constraints and/or influencing interviews' content.

During pretesting, certain other time saving measures were introduced. Print styles and layouts were changed. For certain questions in the network survey, written instructions were

provided. For one question asking respondents to rank a large number of items, a playing card system was utilized. Throughout the pretesting process, team members timed the surveys, taking note of the duration required to complete each scale. Respondents were each asked how they felt the length of the measure had affected their performance.

The second focus of pretesting had to do with the ordering of measures. There was a challenge in organizing the questionnaire in such a way as to provide logical transitions from one scale to the next. To every extent possible, scales were arranged such that respondents considered first themselves, the child in question, and then increasing widening social systems. Each scale's potential for mood induction was considered. And certain potentially reactive measures were left towards the end of the questionnaire.

Finally, pretesting resulted in adjustments to certain measures which had been prepared for the study. It was believed initially that pretesting would have its greatest impact in this area. A whole range of scales requested information on the local service delivery system. Since much of this system exists in the volunteer service sector, it was expected that pretesting would serve the function of actually generating a large portion of the items. As it turned out, the existing literature and information gathered prior to pretesting allowed a fairly comprehensive measure to be constructed. Administration revealed certain areas of unclarity, however. Some were minor. One item, for example,

requested a listing of "services received". In the original, the lines beneath the question were numbered. This left respondents with the impression that they were required to identify a fixed number of services. One question asking about disabilities of family members left it unclear as to whose "relation" was being identified. For a series of questions dealing with family needs, it became evident that respondents would need constant prompts to ensure that their answers were framed around the present.

Some interesting issues arose out of two questions which asked respondents to rate the various services they had received. In some cases, respondents were hesitant to attach a rating to services which were vitally needed, but delivered poorly (eg., a school bus whose schedule is inconvenient). Conversely, some respondents remarked that certain grossly deficient services had had positive aspects in that they employed a particular, exemplary service provider. In the end, respondents in the study were asked to report an overview impression of each service, noting extra, explanatory information (or caveats) adjacent to the rating scales provided. The procedure seemed to reassure respondents that their ratings would neither understate the value of needed services, in their ideal forms, or incriminate good staff of substandard programs.

### 5.3.3 Implementation

For a number of reasons the team wanted the interviews to be administered within as brief a schedule as possible. It was

important that we ensure the smallest possible inconvenience to the agency, and also be able to report to government in a timely way. Beyond this, there were concerns about the potential for history effects. During the period of the study, the Province was actively involved in an initiative to reduce the residential population of a large facility serving mentally retarded adults. Issues concerning the community service sector were occasionally featured in the news, and thus there was concern that media reportage might tend to focus some respondents' opinions on the professional helping system. It was also expected that through self-help organizations, a good number of respondents might happen to know one another and discuss the study as we were performing it.

The importance of having a brief implementation period only intensified the need for detailed, preliminary planning. A comprehensive schedule of tasks was prepared. The group then considered responses to events which might potentially interfere with the study. Child care costs for respondents were budgeted, for example, as were travel costs, given the possibility that sampling might yield out-of-town respondents. Early on, a relatively minor clerical error (which delayed a critical mailout) taught us that we should directly oversee all tasks not performed by team members themselves.

The most significant challenge in administering the questionnaires was in avoiding engaging with the families as a

helper. Each family expressed a need for certain kinds of assistance; but at the same time, having come into this need by way of an essentially random event, few had had any kind of experience with social services. Virtually every family asked practical kinds of questions about the service system.

The questionnaire itself seemed to crystalize respondents' thoughts on the impact of the birth of their disabled child. Few, it seemed, had ever been queried on the effects that caregiving had had on them personally, and on the patterns of their family life. Once asked, most responded very candidly, and at length. A number of the respondents wanted to connect with team members as counsellors. It was often difficult on the one hand to solicit a wide range of sensitive information, and then essentially diffuse discussions by refocussing respondents on the items of the questionnaire. At times, the needs of respondents conflicted with the needs of the interview process. Whenever this seemed to be occurring, respondents were casually reminded that their contributions to the study could potentially influence service design, and then assured that we could have an unstructured discussion at the end of the interview.

In the original research design, mothers were identified as the study's principle respondents. Mothers were to receive more measures than fathers, in particular measures focussing on social networks and social support, marital satisfaction, and family organization. This decision was based on the frequent observation



in family research that of all respondents, mothers tend to provide appraisals of family life which most closely parallel those of impartial observers. For practical reasons, it was also felt best that only one parent should complete all of the measures, with the other caring for the child during roughly the second half of the interview.

Once the interviews were underway, however, we found that fathers were far better and certainly more enthusiastic commentators on family life than we had originally expected. Some even commented on the inherent unfairness of our design. And as it turned out, the children rarely interrupted the interview process. With most interviews being scheduled in the evening, most children either slept or played quietly nearby. About halfway through the interviews, then, we decided to provide additional measures to fathers. Fathers who had been missed were contacted a second time.

It was interesting to observe which of the measures tended to arouse sensitivities in respondents. Originally it was feared that some respondents would react negatively to measures of marital satisfaction and family functioning. In the end, though, none of these turned out to be problematic. Both were placed at the end of the omnibus survey, and by the time respondents reached them they seemed all but inured to personal questions. Instead, the scales which were the most challenging to administer--from the standpoint of mitigating reactivity--were certain ostensibly innocuous scales which happened to be administered to both spouses

at the same time. The most demanding was a scale which asked spouses about the impact of the child's disability on the family. None of the items was particularly intrusive. But in some cases, certain items seemed to lever areas of disagreement between partners. In one instance a literal argument ensued, and as a result partners' answers came from a sort of negotiated settlement, rather than consensus. In most cases partners arrived at common answers without difficulty. However, the occasional conflict did highlight the importance of considering items for their ability to arouse transactions.

#### 5.4 Practicum Outcomes: Analysis of Social Networks and Social Support

Typical of survey research, data analysis revealed certain areas of imperfection in the measures. As an example, in the present study, as in many others, dimensionality was used as a kind of proxy measure of the magnitude and quality of support provided. Thus when family members were found to provide a greater variety of support than did friends, the impression was left that family contacts provided greater support overall. This might be true, however confirming it would have required a separate measure of satisfaction with support from friends.

When the omnibus questionnaire was being prepared, the team considered including the 20 item companion measure to the PSS/Fa, a questionnaire which would have provided information on perceived support from friends. The length of the larger questionnaire required that the measure be dropped, however. Since

this study was completed, a brief multifactor scale of perceived support, showing strong evidence of validity and reliability, was developed. The 12 item MSPSS (Zimet et al. 1988) would have allowed perceived support of both friends and family to be examined in relation to dimensionality findings. A separate factor, "significant other", would have allowed husbands (who were typically said to provide all support types) to be excluded from analysis altogether.

The study would also have benefited from a more focussed investigation of support availability. Respondents were asked whether they lived inside or outside of Winnipeg. The question is inadequate, however, in that given the intense caregiving demands experienced by parents, even minor physical distances might well make contact with friends and family difficult, particularly if the nature of contact was perceived by parents to be optional, that is, not directly related to caregiving, employment, or the maintenance of a household. A simple question on whether families wished they had greater contact with network members might have produced interesting findings.

A number of strategies were found to be useful to the present study. To begin with, there was clear advantage in measuring a wide spectrum of associated constructs, from satisfaction with support to various structural elements of social support networks. Much of the clinical literature suggests that the most valuable dimension of social support is recipient's

subjective appraisal of its quality and abundance. The present study's findings, however, corroborate the less widely held view that beyond perception, certain rather subtle, structural aspects of support networks may confer important advantages as well.

With such an eclectic questionnaire, there was also clear advantage in including measures which had been used in prior clinical research. As Tardy (1985) and others have noted, the most unfortunate quality of the network literature is its lack of clearly defined theoretical and methodological traditions. In the present study, certain of the more interesting findings resulted from simple replication of methods used by Kazak and Wilcox (1984).

I initially had some concern about collecting such a great volume of data on the many members of respondents' networks. Had no trends emerged from the data, it would have been a tremendous waste of time to administer the principle network instrument. As it turned out, however, the measure captured some interesting comparative case findings. In addition, it allowed for a fairly detailed examination of mothers' network members as a separate population, a procedure which had actually not been intended at the study's outset.

It was a very worthwhile exercise to administer the measures in person, rather than through the mail. The experience gave important meaning to the concept of face validity. While it was never explained to respondents which constructs of support networks were being measured, respondents usually unearthed them,

and in the course of completing the measures provided feedback which turned out to be fairly astute in relation to the final findings. As an example, a number of the respondents commented that recording "support types" adjacent to each network member (to provide data on dimensionality) was not as important as identifying the value or meaning of support. Some noted, for example, that certain friends provided only one type of support (eg., socialization), but that that one commodity was immeasurably essential to their well being.

Conversely, a number of respondents found it a revealing exercise to complete the density matrix (a scale which I had originally thought would yield little of value). Creating a pictorial display of the relationships between friends and family members, a number of respondents made observations similar to those of Wilcox (1981), that is, that there were certain positive aspects to the separation of friends and family.

This informal feedback is essential to what can occasionally be a fairly detached, clinical exercise. Initially, my preference had been to somehow incorporate into the study techniques of conventional participant observation, similar to those used by Bregman (1980) in her research into families with disabled children. What I learned from this study was that much of what these techniques can yield can be achieved in the context of a conventional survey, given a conducive setting, detailed planning, and a series of questions which genuinely derive from the needs and experiences of respondents.

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APPENDIX 1:  
SURVEY ON SOCIAL NETWORKS  
AND SOCIAL SUPPORT

INSTRUCTIONS FOR INTERVIEWERS

- 1) Supply general, introductory information to both father and mother, ie., "this questionnaire asks that you provide information about the people who are available to you, and who you would go to, in times of stress..."

Provide questionnaire (page 98) to father, and questionnaire (page 99) to mother.

Direction to father: "Write the name of each such person beside the appropriate category (ie., 'family', 'friends', or 'professionals')."

Direction to mother: Same as above, adding "...and answer the next five questions about each person listed."

Notes:

- Indicate that names are not to be entered in any particular order; all that is necessary is that they be contained within the appropriate categories.
  - Indicate that if a professional helper happens to have initially been a personal friend, or is a family member, she/he should be listed in either of the categories "friends" or "family". The category "professional" is to be used only in the event of relationships which are solely the products of professional, service delivery-recipient transactions.
- 2) Provide questionnaire (page 100) and the accompanying instructions (pages 101 and 102) to mother. Indicate that the rows of this questionnaire are intended to be continuous with those of the former.
- 3) Provide PSS/Fa (pages 103 and 104) to mother.

- 4) While PSS/Fa is being completed, take mother's first questionnaire (page 99) and transpose list of network members to blank matrix (page 105) in the following fashion:

	name 1	name 2	name 3	name 4
name 1				
name 2				
name 3				
name 4				

Using the matrix as a questionnaire, ask mother to place check marks indicating "any kind of ongoing relationship which might exist between the people who have been listed." She would normally start with the first name in column one, and move across the row; then move to the second name in column one, and so on. Check marks are to be restricted to nonshaded areas.

	Contact number	First name, last initial
F A M I L Y	1	
	2	
	3	
	4	
	5	
	6	
F R I E N D S	7	
	8	
	9	
	10	
	11	
	12	
P R O F E S S I O N A L S	13	
	14	
	15	
	16	

Mark the number which best describes how often you have contact with this person:

- 1) once a day
- 2) once a week
- 3) once every 2 weeks
- 4) once a month
- 5) less than once a month

Mark '1' or '2' to indicate that this person lives:  
 1) inside Wpg.  
 2) outside Wpg

	Contact number	First name, last initial	Relationship	Sex	How long have you known this person?	How long have you known this person?
F A M I L Y	1					
	2					
	3					
	4					
	5					
	6					
F R I E N D S	7					
	8					
	9					
	10					
	11					
P R O F E S S I O N A L S	12					
	13					
	14					
	15					
	16					

	Contact number	Types of support	Support 'sharing'	Blocks change
F A M I L Y	1			
	2			
	3			
	4			
	5			
	6			
F R I E N D S	7			
	8			
	9			
	10			
	11			
P R O F E S S I O N A L S	12			
	13			
	14			
	15			
	16			



INSTRUCTIONS

Column 1) Using only the letter 'a' to 'f' indicate the types of support you would normally receive from each person, according to the following descriptions:

- a) Emotional support - someone listening to your private thoughts and feelings regarding a stressful event and/or giving you physical affection.
- b) Material aid support - someone lending you money or the use of some valuable object like a car or an appliance during a stressful event.
- c) Advice and information - someone suggesting what to do or where to get needed information during a stressful event.
- d) Physical assistance - someone helping with jobs around the house, errands, or favours you might need during a stressful event.
- e) Social participation - someone offering you the opportunity to engage in pleasant social activities during a stressful event.
- f) Respite - someone occasionally taking charge of your responsibilities at home, so you can attend to tasks on your own or enjoy some time at recreation.

You may need to mark down more than one letter per person, but please mark at least one.

Column 2) Write in the number which best describes how support is shared between you and each person you have listed. The 'types' of support you share are unimportant here; you are simply answering:

"For the most part...

- 1) "I provide all of the support in my relationship with this person.
- 2) "I provide more support to this person than she/he provides to me.
- 3) "This person and I give each other about equal amounts of support.

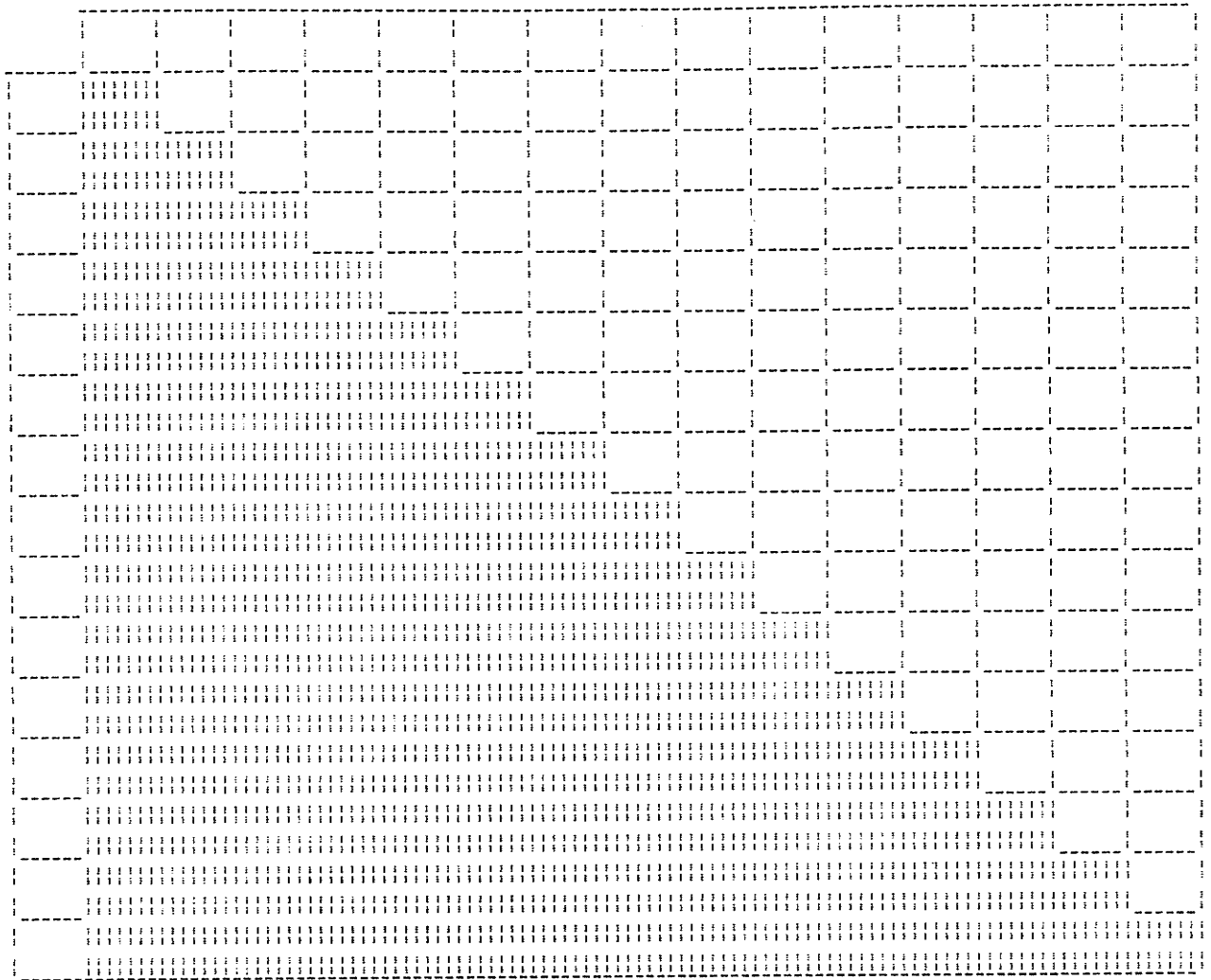
- 4) "This person provides more support to me than I provide to her/him.
- 5) "This person provides all of the support in my relationship with her/him.

Column 3) Place an "X" if you feel this person keeps you from changing (makes you feel uncomfortable, influences you negatively, keeps you stuck).

Directions: The statements which follow refer to feelings and experiences which occur to most people at one time or another in their relationships with their families. For each statement there are three possible answers: Yes, No, Don't know. Please circle the answer you choose for each item.

- |     |    |            |   |
|-----|----|------------|---|
| Yes | No | Don't know | 1. My family gives me the moral support I need  |
| Yes | No | Don't know | 2. I get good ideas about how to do things or make things from my family.   |
| Yes | No | Don't know | 3. Most people are closer to their family than I am.  |
| Yes | No | Don't know | 4. When I confide in the members of my family who are closest to me, I get the idea that it makes them uncomfortable. |
| Yes | No | Don't know | 5. My family enjoys hearing about what I think.   |
| Yes | No | Don't know | 6. Members of my family share many of my interests.   |
| Yes | No | Don't know | 7. Certain members of my family come to me when they have problems or need advice.                                    |
| Yes | No | Don't know | 8. I rely on my family for emotional support.   |
| Yes | No | Don't know | 9. There is a member of my family I could go to if I were just feeling down, without feeling funny about it later.    |
| Yes | No | Don't know | 10. My family and I are very open about what we think about things.   |
| Yes | No | Don't know | 11. My family is sensitive to my personal needs.  |
| Yes | No | Don't know | 12. Members of my family come to me for emotional support.  |
| Yes | No | Don't know | 13. Members of my family are good at helping me solve problems.   |
| Yes | No | Don't know | 14. I have a deep sharing relationship with a number of members of my family.   |
| Yes | No | Don't know | 15. Members of my family get good ideas about how to do things or make things from me.                                |
| Yes | No | Don't know | 16. When I confide in members of my family, it makes me uncomfortable.  |

- Yes No Don't know 17. Members of my family seek me out for companionship.
- Yes No Don't know 18. I think that my family feels that I'm good at helping them solve problems.
- Yes No Don't know 19. I don't have a relationship with a member of my family that is as close as other people's relationships with family members.
- Yes No Don't know 20. I wish my family were much different.





How much assistance will this child require over the years to perform everyday activities like eating, bathing, toileting?

very little	a moderate amount	frequent	constant
1	2	3	4

FAMILY INFORMATION:

Family type:            \_\_\_ two parent            \_\_\_ single parent  
                          \_\_\_ nuclear            \_\_\_ blended            \_\_\_ extended  
                          \_\_\_ biological            \_\_\_ adoptive

Please list ALL FAMILY MEMBERS living in your house, their AGES, EDUCATION and whether or not they are EMPLOYED.

DO NOT COUNT YOUR FAMILY MEMBER WITH A DISABILITY IN THIS LIST BUT REMEMBER TO INCLUDE YOURSELF. Please only write down the family member's relationship to the disabled person (mother, father, aunt, brother, grandmother, etc.) NO NAMES PLEASE.

Relationship	Age	Education	Employment Status		
			Employed Full Time	Employed Part Time	Not Employed
1.	_____	_____	_____	_____	_____
2.	_____	_____	_____	_____	_____
3.	_____	_____	_____	_____	_____
4.	_____	_____	_____	_____	_____
5.	_____	_____	_____	_____	_____
6.	_____	_____	_____	_____	_____
7.	_____	_____	_____	_____	_____
8.	_____	_____	_____	_____	_____

What was the total taxable family income last year (1985) of primary wage earners in your household (please check one only)

- |                        |                       |
|------------------------|-----------------------|
| ___ \$ 0 - 9,999       | ___ \$30,000 - 39,999 |
| ___ \$ 10,000 - 19,999 | ___ \$40,000 - 49,999 |
| ___ \$ 20,000 - 29,999 | ___ \$50,000 or more  |

What is the postal code area of your home?    \_\_\_ \_\_\_ \_\_\_ \_\_\_ \_\_\_



WHEN WE FACE PROBLEMS OR DIFFICULTIES IN OUR FAMILY, WE RESPOND BY:

---

RESPONSE CHOICES

- | 1                 | 2  | 3                          | 4                | 5              |
|-------------------|--|----------------------------|------------------|----------------|
| Strongly Disagree | Moderately Disagree  | Neither Agree Nor Disagree | Moderately Agree | Strongly Agree |
| 1.                | Sharing our difficulties with relatives.   |                            |                  | _____          |
| 2.                | Seeking encouragement and support from friends.  |                            |                  | _____          |
| 3.                | Knowing we have the power to solve major problems.   |                            |                  | _____          |
| 4.                | Seeking information and advice from persons in other families who have faced the same or similar problems. |                            |                  | _____          |
| 5.                | Seeking advice from relatives (grandparents, etc.).  |                            |                  | _____          |
| 6.                | Asking neighbours for favours and assistance.  |                            |                  | _____          |
| 7.                | Seeking assistance from community agencies and programs designed to help families in our situation.        |                            |                  | _____          |
| 8.                | Accepting that we have the strength within our own family to solve our problems.                           |                            |                  | _____          |
| 9.                | Accepting gifts and favours from neighbours (e.g., food, taking in mail, etc.).                            |                            |                  | _____          |
| 10.               | Seeking information and advice from the family doctor.   |                            |                  | _____          |
| 11.               | Facing problems "head-on" and trying to get solutions right away.  |                            |                  | _____          |
| 12.               | Watching television.   |                            |                  | _____          |
| 13.               | Showing that we are strong.  |                            |                  | _____          |
| 14.               | Attending church services.   |                            |                  | _____          |
| 15.               | Accepting stressful events as a fact of life.  |                            |                  | _____          |
| 16.               | Sharing concerns with close friends.   |                            |                  | _____          |
| 17.               | Knowing luck plays a big part in how well we are able to solve family problems.                            |                            |                  | _____          |

18. Accepting that difficulties occur unexpectedly. \_\_\_\_\_
19. Doing things with relatives (get-togethers, dinners, etc.). \_\_\_\_\_
20. Seeking professional counselling and help for family difficulties. \_\_\_\_\_
21. Believing we handle our own problems. \_\_\_\_\_
22. Participating in church activities. \_\_\_\_\_
23. Defining the family problem in a more positive way so that we do not become too discouraged. \_\_\_\_\_
24. Asking relatives how they feel about problems we face. \_\_\_\_\_
25. Feeling that no matter what we do to prepare, we will have difficulty handling problems. \_\_\_\_\_
26. Seeking advice from a minister. \_\_\_\_\_
27. Believing if we wait long enough, the problem will go away. \_\_\_\_\_
28. Sharing problems with neighbours. \_\_\_\_\_
29. Having faith in God. \_\_\_\_\_

Listed below are a number of statements concerning personal attitudes and traits. Read each item and decide whether the statement is true or false as it pertains to you personally and circle either T or F.

- T F 1. I never hesitate to go out of my way to help someone in trouble.
- T F 2. It is sometimes hard for me to go on with my work if I am not encouraged.
- T F 3. I have never intensely disliked someone.
- T F 4. On occasion I have doubts about my ability to succeed in life.
- T F 5. I sometimes feel resentful when I don't get my way.
- T F 6. If I could get into a movie without paying for it and be sure I was not seen, I would probably do it.
- T F 7. There have been times when I felt like rebelling against people in authority even though I knew they were right.
- T F 8. I can remember "playing sick" to get out of something.
- T F 9. There have been occasions when I took advantage of someone.
- T F 10. I'm always willing to admit when I made a mistake.
- T F 11. I always try to practice what I preach.
- T F 12. I don't find it particularly difficult to get along with loud mouthed, obnoxious people.
- T F 13. I am always courteous, even to people who are disagreeable.
- T F 14. I never make a long trip without checking the safety of my car.
- T F 15. There have been times when I have been quite jealous of the good fortune of others.
- T F 16. I have almost never felt the urge to tell someone off.
- T F 17. I sometimes think when people have a misfortune they only got what they deserved.