

**Community Participation in Identifying Needs of
Developmentally Delayed or At-Risk Indian Children in
Northern Saskatchewan**

A Thesis

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ABSTRACT

Each child has innate abilities. How the child functions, however, is dependent on the type and quality of the child's environment. Policies and practices of non-native society have greatly affected the environments in which Indian children have grown up. In the past, Indian children with disabilities were taken from their families and traditional communities and placed in foster homes near necessary services. Only recently have decision-makers begun to acknowledge the importance of the natural family, the cultural heritage and the environment, and the dynamic interactive relationship between them.

In this study, nine members of a small northern Indian community were interviewed. They shared their perceptions of the needs of children in their community, and provided insight into what aspects of their community need to be considered when developing culturally relative intervention strategies.

Most participants expressed concern for the well-being of all children, and felt that children should be viewed as the community's greatest resource. Associated with this concern was a shared genuine concern about parenting and the effects of poverty, abuse and neglect. All participants stressed that

children with disabilities and their families need support from, involvement with, and acceptance by the community, particularly by those who are in decision-making roles. Study participants also expressed some concerns about the usefulness of non-native formal systems of support and identified what they saw as barriers to access of the formal system. As well, study participants articulated specific difficulties in dealing with certain professionals. These difficulties resulted from language barriers, cross-cultural issues, feelings of intimidation, and lacking the confidence to express their concerns.

This study has given us some insights into a community's perspective on the needs of children and their families. The challenges which have come forward from this study are two-folded: the need to explore and develop parental practices based on traditional values, but appropriate for dealing with the influences of today's world; and the need to support communities in their efforts to take on the primary responsibility for child welfare matters.

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FOREWORD

I have had the opportunity to work in the field of early childhood intervention for the past fifteen years, most of them in Saskatchewan. For seven of these years I have been in the position of Program Director of the Early Childhood Intervention Program at the Kinsmen Children's Centre, Royal University Hospital, Saskatoon. This centre serves the central and northern regions of the province. My work has enabled me to travel and act as a consultant to many of the Early Childhood Intervention Programs in the Province.

On a provincial level, I have been involved with issues relating to how early intervention services can best be provided to children and families. As well, working at the Kinsmen Children's Centre has enabled me to come in contact with many Indian children and their families. Observations and dialogue with these people have raised many questions in my mind with respect to providing services to them. These are the sources of my interest in early intervention services for Indian children.

In my initial contact with the community I asked the community members what term of reference they use for themselves. Members of this community prefer to

refer to themselves as Indian, and it is for this reason that I have chosen to use the term Indian in this study.

CHAPTER 1

OVERVIEW OF THE STUDY

Introduction

The last twenty years have produced substantial research and information in the area of early childhood development, particularly on the influences of early experiences on the developing child. Each child has innate abilities. However, what the child does, or how it functions, is dependent on the type and quality of its environment. As Bloom (1986) writes, having "normal" potential is not in itself a guarantee that a child will develop normally. The important ingredients become the opportunity for the child to interact in a positive manner with family or other care-givers; to experience and enjoy intellectually and emotionally satisfying events; and to have interesting objects with which to experiment and explore (Bloom, 1989).

"Early intervention" is a term used to describe programs whose goal it is to prevent or ameliorate developmental problems which may result from environmental or biological influences or both (Dunst,

Snyder & Mankinen, 1988). The understanding is that with mediation one can expect a different developmental outcome than had there not been mediation. In early intervention the mediation process is started as soon as a (potential) problem has been identified or as early as needed. Early intervention services include experimental, educational, and therapeutic treatments, training procedures, and avenues for formal and informal support.

Indian children with developmental delay have for the most part received intervention services outside of their home communities. Through this practice, the responsibility for developmentally delayed Indian children has shifted away from community and kinship networks, often leaving individual parents or couples to shoulder the responsibility alone (Manitoba Metis Federation Inc., 1986).

The intent of this study is to bring together our knowledge of what early intervention does generally for children, with what Indians in the study community identify as critical to meeting the needs of their children.

Background to the Study

Early Intervention in Saskatchewan

The 1960's was the starting point for home-based intervention services (Zaleski and Gallagher, 1975). The first individuals who provided these services in Saskatchewan were a small group of social workers and public health nurses in a number of areas in the south and central parts of the province. In 1967 the Alvin Buckwold Centre (ABC), a diagnostic centre for the mentally retarded at the University Hospital in Saskatoon, was established. As well as providing diagnostic services it provided home-based programs to families within a 160 km radius of Saskatoon. An ABC preschool program was established in 1973 and a home based early intervention program in 1977 (Bloom and Glazer, 1985). The continuation of these programs were dependent on research grants provided by both the federal and provincial governments.

The SEEC Preschool Project (Bloom, 1978), carried out by the Institute of Child Guidance and Development, College of Education, University of Saskatchewan, supported the concept of early educational intervention in the home. It concluded that intervention had;

- (1) enhanced the rate of development of most of the children while they were enrolled in the project and
- (2) provided positive attitudinal change in parents towards their perceived ability to help their child and to exert some control over their own situation.

Based on the positive results of the SEEC Project and the ongoing support of the programs at the Alvin Buckwold Centre, the Saskatchewan Association for Community Living (SACL), an organization of parents, became interested in helping to develop further community-based early intervention services throughout the province of Saskatchewan. In 1980, with initial seed money from SACL and the Alvin Buckwold Centre, the first parent and community operated Early Childhood Intervention Program (ECIP) was established in Prince Albert (ECIP Standard and Guidelines, 1989). The next six years saw the development of ECIPs throughout south and central Saskatchewan. At any given time these 16 ECIP's serve approximately 500 children in Saskatchewan who have been diagnosed as being developmentally delayed or at risk for developmental delay.

Though these programs operate as independent,

non-profit, community boards, they are tied together by a provincial body, the ECIP Provincial Council. This body together with representatives from each ECIP board, the Departments of Social Services, Health, Education, Indian Affairs, and representatives from SACL, advise on policy decisions for program development and operations in the ECIPs.

The philosophy of ECIPs in Saskatchewan is that all children with developmental delays or at risk for delay, regardless of the severity and nature of their disabilities, can benefit from early intervention (ECIP Standard and Guidelines, 1989). In addition, the families of these children are viewed as being the primary agents for meeting their child's needs. They are encouraged to exercise their right to act as advocates on behalf of their children, and have the right to all information, resources and services which pertain to their child's disability (ECIP Standard and Guidelines, 1989).

Saskatchewan is just one of four provinces which has province-wide ECIP services. The other three are British Columbia, Ontario and most recently Alberta.

Structure of ECIP's

The approach of the Early Intervention Programs in Saskatchewan is to provide home-based intervention, by working in partnership with parents to enhance the development of their child (ECIP Standard and Guidelines, 1989). All ECIPs have an open referral policy. Referrals come from physicians, public health nurses, social workers, psychologists and from parents themselves.

Each child and its caregiver(s) are visited in the home regularly, generally every two weeks. An individual service plan is developed, based on assessment information from both ECIP and other professionals, and the parent's goals and objectives. The implementation of this plan is primarily carried out by the parents. Objectives are those which are easily adapted to the daily routine of the child and family.

Since many of the children in ECIP's have a wide range of developmental problems, consultation with other services such as occupational therapy, physical therapy, speech and language services, social work, physicians, is critical for developing a comprehensive service plan. Each ECIP serves families both in urban and rural settings. For those programs which are located in major

urban centres both the number and type of alternative services, and accessibility to these services is greatly facilitated. Those programs, which are largely rural, often have greater difficulty in accessing appropriate consultative services. As a result, the staff in these programs work in greater isolation and the children and families have fewer resources available to them.

Needs of Northern Residents

The difficulties of distance and isolation become even greater when one considers the vast expanse of northern Saskatchewan. Most health services for the northern region are provided in Saskatoon. Since many children with disabilities require consistent monitoring from a wide variety of health professionals, this task becomes difficult for the professionals, and more so for the families. Under the present system, frequent long trips to Saskatoon are required for brief appointments. The coordination of travel and appointments is not always done to the family's benefit. Consideration of care for family members who are left at home, the length of travel time, and appropriate accommodation while in Saskatoon are only some of the issues which require addressing.

There are other factors which are often overshadowed by the logistics of having families travel to Saskatoon. Families may not understand the reason for the appointment, nor the underlying problem(s). Culturally different and unfamiliar settings might also cause stress. A very contentious issue has been the removal of Indian children from their northern homes for medical treatment at large urban centres, thus requiring foster home placement (Connors, 1988; Cross, 1989; Haig-Brown, 1989; Ross, 1992).

Indian Children: An Historical Perspective

Removal of Indian children from their families and home community has strong historical roots (Haig-Brown, 1989; Miller, 1987; Ross, 1992). It was common practice in the past for Indian children to go to residential schools to be educated with the option of returning back to the community once the education was complete or, as often happened, the individual dropped out of school.

The same practice of removal occurred if an Indian child from northern Saskatchewan had a medical problem which required monitoring or ongoing therapy. The practice was to place the child in a medical foster home, usually in Saskatoon, the centre for northern

health referrals. The decision for placement was generally made by medical professionals. Funding to support the child in the foster home would then be provided by either Health and Welfare Canada or Indian Health Services. Parents' or the community's involvement in the decision making process was absent; or if present, was a "token" involvement (Hamilton, Shelley, 1992; Social Worker, personal communication).

Children with diagnosed motor development problems (nervous system/muscle) would often be placed in foster care to attend special classes at the Children's Rehabilitation Centre in Saskatoon. Once they reached the age of 18 years and their schooling was finished these children were usually returned to their birth communities. This practice led to major adjustment problems not only for the children, who had become teenagers, but for their families and home communities.

The negative impact of removing children from their families and home communities is of major concern to the Indian communities and the department of Indian and Northern Affairs. Not only have these children often suffered major emotional and identity problems as a result of this practice (Ross, 1992), but the removal of children has also prevented parents and communities from

dealing with the responsibilities and challenges of trying to meet the needs of their developmentally delayed children.

Though there continue to be some children who are placed in medical foster homes, the numbers are becoming fewer and the decision making process involves more individuals than in the past (Wolfom, Mardell, 1992; Social Worker, personal communication). Generally, representatives from the child's community and the family are actively involved before a final decision is made. As well, the parents have the right to review the placement at any time.

A more common occurrence now, is that children with developmental problems remain at home with their families in their communities and continue to receive monitoring and therapy services from Saskatoon. It is not uncommon for many of these families to make the trip to Saskatoon once every two weeks for physical therapy and perhaps occupational therapy. Families are flown in from as far north as Black Lake and Uranium city for these appointments. For families from communities which are not on flying routes, nine or more hours of bus travel is required to make the trip to Saskatoon. Bus travel is generally the the only option for families

from the north eastern part of the province.

A major question that professionals should be asking is "What is the impact of this service delivery system on the child and family?". In addition there are other related questions: What supports are necessary to make this experience as profitable as possible for all involved? Should services be provided in the communities? Would the dollars be better spent sending professional teams to the north on a regular basis, as opposed to paying for individual families to make frequent trips to the south?

These questions are beginning to be asked by various elements or groups in Indian communities, and those in government (LaRocque, Archie, 1991, Social Development Indian and Northern Affairs Canada, personal communication) who are involved with arranging for the funding for these services.

Northern Services.

Travelling clinics. Travelling clinics to the north occur on an infrequent basis, and are dependent on limited funding. The Alvin Buckwold Centre (ABC) has provided diagnostic and developmental assessment clinics to some of the northern communities. These services do

not include regular follow-up or review appointments in the community. Families are generally required to travel to Saskatoon for follow-up and review services.

Ear nose and throat specialists and audiologists provide some travelling clinic services to the north. This clinic is involved primarily with diagnosis, as opposed to regular follow-up and review.

Another team which has recently begun travelling to the north is the neonatal follow-up team. Only infants who were born prematurely and are not in need of regular medical intervention are provided this service. Those neonates who require regular medical monitoring have to make frequent trips to Saskatoon.

Indian Health services. Most larger reserves in northern Saskatchewan have their own nursing stations (Lammer, Harvey, 1991, Social Development Department of Indian and Northern Affairs Canada, personal communication). Some nursing stations are staffed by fly-in personnel who are on a regular rotation, while others have staff who reside in the community on a permanent basis. Physicians generally fly into the larger communities on a regular schedule. In medical emergencies, patients are flown out to a major hospital.

Social Services. Social workers drive from La

Ronge to most northern reserve communities (Mayote, Michelle, 1991, Social Worker, personal communication). Services are often provided via telephone to more remote areas, which are not accessible by road. Social workers occasionally fly in if there is an extra seat on a plane already flying to the community. Lack of funding prevents more systematic servicing. Traditionally, social service involvement with Indian families with developmentally delayed children has dealt with child care or child protection issues, and accessing funds to coordinate appointments outside the community.

The Department of Social Services, Community Living Division, provides one social worker to support and coordinate services for developmentally delayed individuals in all of northern Saskatchewan.

Early Childhood Intervention services. At present there are two ECIPs which provide services to children with developmental delays in northern Saskatchewan (ECIP Standard and Guidelines, 1989). Since the ECIPs are provincially funded, children who are under the jurisdiction of Indian and Northern Affairs are not automatically served by these programs. Indian and Northern Affairs has the option of purchasing services from the ECIPs, however, and the early intervention

needs of many children are met in this manner.

The Children North ECIP serves children in the La Ronge area. Some services from this program are provided to the northern central region of the province if the staff are able to fly into the community with the doctors during their fly-in clinic times.

The Wecihik Awasisak ECIP operates out of Ile a la Crosse and serves communities in the north-western part of the province which are accessible by road.

At present, communities in the north-eastern region of the province are not served by ECIPs.

Significance of the Study

The information resources from which many of the existing early intervention programs gain the knowledge used to develop individual programs are often based on research done with traditional Caucasian families. Consequently, suggested models for parent child interactions, parent modelling of behaviours or the choice of developmental activities may be inappropriate or lack cultural relativity (i.e., not appropriate with respect to the context of the culture of Indian

children). Information on Indian culture, particularly customs, beliefs and values relative to the child, the family and the community is essential to developing culturally relative intervention strategies.

This study is important with respect to the current difficulties associated with providing services to northern families. These difficulties mentioned previously include:

- (1) foster placement of Indian children to access medical services,
- (2) urban-based services for children with developmental delay, which necessitates significant travel, and
- (3) limited community-based resources directed by community members.

Purpose of the Study

With respect to the the needs of children with developmental delay or at risk for delay, and their families in northern Saskatchewan, two of the most important questions which need to be addressed are:

- (1) What are the perceptions of community members concerning the needs of children in their

community?

- (2) What aspects of a small northern Indian community need to be considered when developing culturally relative intervention strategies?

The intent of this research study was to address these questions by actively involving selected individuals from one northern Indian community in the study. Their insights and perspectives could help to identify the problems and plan solutions. Increased participation could also lead to a decrease in feelings of alienation and lack of involvement, and feelings of powerlessness in the decision-making process relating to services for developmentally delayed children in their community.

Definitions

Developmental delay is defined as "a significant delay" (more than one standard deviation below what would be expected of a child of his/her chronological age) in one or more areas of development (Bloom, 1989).

At risk for developmental delay are children who because of conditions prenatally, at birth, or in the home, might be expected to experience developmental problems (ECIP Standard and Guidelines, 1989). The three major categories are:

- a) "Established risk" concerns diagnosed disorders where the condition is known to affect development (e.g., Down Syndrome, Hydrocephalus).
- b) "Biological risk" concerns prenatal, perinatal and neonatal events which may affect development (e.g., prematurity, low birth weight, abnormal neurological findings).
- c) "Environmental risk" concerns high risk environmental influences that may affect development (e.g., parent substance abuse, adolescent parenting, psychiatric stress).

Culture is defined by Randall-David (1989) as a group of people with common origins, and customs that have a shared history and experiences which shape the group's values, goals, beliefs, expectations, perceptions and behaviours.

Cultural relativity refers to the idea that behaviour should be judged in relation to the context of the culture in which it occurs (Randall-David, 1989).

Culturally competent refers to respecting beliefs, interpersonal styles, attitudes and behaviour of a culture and incorporating these values into policies, administration and practice (Roberts, 1990).

The study community is actually the subcommunity, or elements of the community, involved in any way with the care of children.

CHAPTER TWO

REVIEW OF THE LITERATURE

The literature review for this study will focus on three major areas: 1) efficacy studies of early intervention, 2) the two major approaches to early intervention, child-focused intervention and family-centered social support and 3) early intervention with Indians and to a lesser extent, other ethnic minorities.

Efficacy of Early Intervention

Early childhood intervention programs are firmly established in Saskatchewan because of efficacy studies which support the logic of early intervention and demonstrate positive impacts on child development. Reviews such as Bush and White (1983), and Castro and White (1985) integrate data from previous efficacy studies. Their conclusions about the effectiveness of early intervention were based largely on studies of at-risk children from lower socioeconomic (disadvantaged) backgrounds.

Other reviewers, (Bloom, 1986; Castro and Mastropieri, 1986; Chamberlin, 1987; Dunst, Snyder & Mankinen, 1988; Swift, Fine & Beck, 1985;) have arrived at similar positive conclusions from studies of developmentally delayed children as well as of at-risk children. Differences between reviews of early intervention have not been on the question of "Does early intervention make a difference?" but rather on the variables associated with intervention effectiveness. The efficacy study by Dunst et al. (1988) summarized 11 major conclusions, eight of which are universal to the other efficacy studies (see above). These eight conclusions are listed below:

- (1) The majority of children participating in early intervention make developmental progress. However the extent to which the intervention is responsible for the change is difficult to determine.
- (2) The most conclusive efficacy evidence comes from studies of environmentally at-risk children.
- (3) Cognitively and behaviourally oriented programs seem to produce the greatest effects.

- (4) Certain variables have been associated with intervention effectiveness (age of entry, intensity and duration of intervention). These will differ based on the type of intervention program and its population base (i.e. environmentally at-risk, biologically at-risk).
- (5) The rate of progress differs as a function of the severity of the child's impairment; the more severely impaired the slower the rate of progress.
- (6) The best indicator of the degree of progress is entry level performance; higher functioning brings about greater gains.
- (7) Parent and family characteristics, including education level, socioeconomic status, income and family size influence the child's progress. This is more evident for programs for heterogeneous at-risk infants than environmentally at-risk infants.
- (8) Mediational effects in parent and family functioning are stronger than in child functioning. Both the formal and informal components of support from the intervention

programs and the outside sources of support contribute to these effects.

Most efficacy studies have focused on IQ measures as indicators for judging the effectiveness of early intervention. Researchers are in general agreement that this is a limitation of the research (e.g., Castro and Mastropieri, 1986; Dunst et al., 1988). Swift et al. (1985) used improvement in the personal social behaviours of children as indicators of the effectiveness of early intervention. Other intervention studies, for example Weikart (1980), have suggested the cost effectiveness of early intervention as a reasonable measure of its effectiveness by projecting lower educational costs and increased lifetime earnings.

In addition to the evaluation data from efficacy studies, data found in the human development literature provide a research base for early intervention (Anastasiow, 1986; Hunt, 1961; Kirk, 1958; Montessori, 1949; Piaget, 1952).

Approaches to Early Intervention

Though the efficacy question continues to be asked, the majority of research on early intervention is

now focusing on "how" to deliver services and what type of service to deliver. Early intervention services can be grouped into two major categories. The first type includes those which are primarily child-focused, developmental in orientation and are evaluated on the basis of the performance of children. The second type consists of those which are family-centered, and evaluated by family stability, family coping and social functioning, in addition to the progress of the children.

In the child-focused approach, mediation often occurred in isolation from the context of the child and family. This is apparent in the early definitions of early intervention. For example, Denoff (1981) defines early intervention in terms of providing instructional children's activities to children at risk for a variety of conditions. Goals were generally child focused and pre-planned, geared to attainment of major developmental milestones.

Dunst (1985), Slater and Wikler (1986), Dunst et al. (1988) and others have expanded the definition of early intervention to include other mediating events which are influential in affecting a child's behaviour and development. Dunst et al.(1988) describe the

approach as "the aggregation of the many different types of help, assistance, services and so forth provided to families by individuals and groups" (p. 752). This orientation is often referred to as family-focused social support intervention.

Dunst (1985) uses a social systems conceptual framework as the underlying structure for the family focused intervention. This framework suggest that "events in different social units do not operate in isolation but affect one another both directly and indirectly so that change in one unit will impact upon other units (Trivette and Dunst, 1987, p.391). The social systems conceptual framework involves the integration of theoretical formulations from human ecology (Bronfenbrenner, 1979), social network theory (Mitchell and Trickett, 1980), help seeking theory (Gourash, 1978) and models of stress and coping (Crnic, Freidrich and Greenberg, 1983).

Sigel (1985) highlighted both child and family characteristics as critical factors to the beneficial outcome of intervention. Parental belief systems (attitudes, values, self-concepts) were found to have both direct and indirect influences on child behaviour and development.

Stress, and coping with stress, have become recognized as critical factors in determining intervention effectiveness. As Slater and Wikler (1986) point out, the extraordinary caretaking demands of many developmentally delayed children put parents at risk for added stress, social isolation and reduced feelings of autonomy and self-concept. To meet the needs of these families other support services are critical and often more important than the child's specific developmental needs (Dunst, 1985). Yoder (1990) found that provisions for adequate social support were effective in reducing stress and increasing feelings of well-being among families of developmentally delayed children.

Researchers such as Dunst et al. (1988) and Guralnick (1989) see family-focused intervention as a more efficient approach to the provision of services. Early intervention programs are seen by Zeitlin and Williamson (1986) as "one component of a whole continuum of services that are needed by the child and family" (p. 57). As the needs of children and families change, so too should the services change in order to more appropriately meet the needs of the children and families.

Working with families has evolved along a continuum

from professional-centered, to family-involved, to family-focused to now family-centered (Pletcher, 1991). In family-centered practice the family has the central role in the development of their child (Bailey, 1987; Bailey & Simeonsson, 1988; McWilliam & Bailey, 1993), thus recognizing the relationship among family members and between the family and the community in order to maintain or improve the well-being of the family unit as a whole.

Family adjustment is an important component of family-centered practice. Trute (1988, 1990) concludes from his studies that positive family adjustment has little relationship to specific child attributes (gender, age, level of disability). Variables which affect family adjustment include marital adjustment, education level of care-givers, and informal support systems (family and friendship network). To promote positive family adjustment emphasis needs to be placed on mobilizing, and strengthening parental subsystems, and developing parental skills in the utilization of their informal support network (Trute & Hauch, 1988a; 1988b).

Advocacy movements, rooted in the values of a group of individuals, have become strong proponents of

family-centered practices and research. These groups strongly support new developments and implementations in teaching and providing therapy to include naturalistic or incidental strategies and integrated therapy (therapy in the natural setting) (McWilliam & Bailey, 1993). In addition to looking at the developmental needs of the child, other factors such as the family's values, priorities, available resources, both within the family and their informal support networks, and the structure and availability of other community resources need to be considered (Bailey et al., 1990).

According to Hobbs et al., (1984) and Halpern, (1990) supportive communities are central to promoting human development and strengthening family functions. Thus, community participation should be sought, in the challenge of meeting the needs of developmentally delayed children in each community. The nature of the participation will depend on the needs of the children.

Public Law 99-457 in the United States legislated the inclusion of families in the decision making and program development of services for children with disabilities. In addition, programs which strive to incorporate the values and practices of family-centered care need also to incorporate cultural competence into

their philosophical and practical orientations to ensure that certain cultural groups are not being underserved (Cross, 1989; Roberts, 1990; Pence, 1992). Cultural patterns are deeply ingrained systems of social behaviour and beliefs which effect learning (Cross, 1989, Roberts, 1990). In addition to being determinants of behaviour, cultural patterns influence what types of daily routines a family may choose to adopt. Gallimore et al., (1993) emphasizes the importance of daily routines and social interactions in organizing and shaping children's activities and development. Everyday routine and development-sensitive interactions do not exist in isolation of the family's cultural environment (Roberts, 1990; Gallimore et al., 1993). Therefore what is learned, how learning occurs, and from whom and individual learns, may vary depending on the situation and the cultural patterns rooted within a family and the community.

Early Intervention with Indian Children and Families

There is limited literature on studies of early intervention with Indians. Mayfield (1985) reports on an Indian infant program which began in 1981 with five

Indian Bands in British Columbia. This project was initiated by the Bands and focused on home-based early intervention and parent education. Indian women from the community were trained to implement a program using Indian cultural values and traditional child-rearing practices to help parents enhance the development of their children. The children in the program were from new-born to four years of age with no known established or biological risk for developmental delay. However, they did fall into the category of environmental risk for developmental delay.

An evaluation of the program found positive feedback from parents in their increased awareness of child development and increased family involvement with program activities. Mayfield (1985) identified four key factors necessary for successful planning and implementing of early childhood programs for non-developmentally delayed children in Indian communities. These were:

- (1) The program needs to be initiated by the community, based on its perceived needs.
- (2) The program needs to be culturally relative. Community elders should be involved because their expertise and knowledge could help

increase local interest, acceptance and participation. Combining traditional child-rearing practices with child development knowledge is effective and preferable.

- (3) Training local Indian people strengthens the cultural relativity of the program and provides effective role models in the community.
- (4) Active parent participation is a critical factor.

Mayfield (1985) concludes that programs such as these may help prevent future developmental delays and increase success in future formal schooling.

To date, literature searches have produced no evidence of studies of early intervention with developmentally delayed Indian children. This supports the need for my study of intervention possibilities for developmentally delayed children and their families, as perceived by elements of an Indian community.

Many authors cite the need to support Indian parents (Connors, 1988; Halpern, 1990; Mayfield, 1985; Northwest Indian Child Welfare Institute, 1990; Ross,

1992) during what is sometimes described as a transition time. These authors feel that the growth and well-being of Indian children is best promoted by exploring the values and traditional Indian child-rearing practices and blending these values with contemporary influences in parenting.

CHAPTER THREE

RESEARCH DESIGN AND METHODOLOGY

Design of the Study

Naturalistic inquiry (Guba and Lincoln, 1982) is the method used in this study. The distinguishing features of this form of inquiry are that the inquiry is carried out in a natural setting, uses a case study format and relies on qualitative data. Since a naturalistic study relies on the process as well as the outcome to give it meaning (Bogdan and Biklen, 1982), it was well suited to the type of study I wished to pursue.

An important concept in naturalistic inquiry is the idea of "meaning" and how it is negotiated. Bogdan and Biklen (1982) define meaning as "the ways in which different people make sense of their lives" (p.29). One focus of my study was to obtain insight into what it "means", for certain individuals in the study community, to have one or more developmentally delayed children in their midst. (What were their norms and expectations for these children and how did they arrive at these?).

In naturalistic inquiry the researcher is the

"instrument" for data collection (Lincoln and Guba, 1985). This form of data collection has some limitations which need to be addressed. The issue of the effects of the observer (observer effect), the presence of the researcher changing the behaviour of the participants and therefore influencing the results of the study (Bogdan and Biklen, 1982), is a problem to be considered. However, observer effects are not unique to naturalistic research. In this study, I tried to minimize my effect on the responses of participants by interacting with the participants in a manner which was culturally-appropriate, natural, unobtrusive and as non-threatening as possible.

Because naturalistic research is contextual, it is not designed to offer generalizations. The findings from this study will only be applied to the community in which it was conducted. Other readers, however, may find some elements of the study which they are able to transfer to other communities.

Study Format

This research project takes the form of a case study of a community, trying to gain insight into the less visible everyday life of children in the community.

According to the format of Yin (1989) the case study will:

- 1) investigate a contemporary phenomenon within its real context,
- 2) reinforce that the boundary between the phenomenon and the context do not exist independent of each other, and
- 3) use multiple sources of evidence (listed below in data collection) to strengthen the data, often referred to as "triangulation".

Methodology

Access to Site

Much of the negotiations to gaining access to the study community were done verbally because the traditional culture of the community is oral. Formal written procedures, initially intended by the researcher, were not used because the community wished to negotiate verbally.

Initial contact was made with the community through a telephone conversation with the Health Nurse. During this contact a verbal overview of the project was shared

and the information was forwarded via the Health Nurse to the Health Committee.

On July 8th, 1991, the author was invited to meet with members of the Health Committee at which time a formal presentation of the proposed research was made. During this meeting, the Chairman of the Health Committee asked questions relating to the project. A written outline of the project was left with both the Health Nurse and the Chairman of the Health Committee. The Health Committee then forwarded the information to Chief and Council. Verbal approval to proceed with the project was given by Chief and Council on July 15th, 1991.

The researcher met with the Health Nurse in September, at which time more information was shared regarding the interview content and the proposed procedure. The Health Committee proposed a list of possible interview participants which the Health Nurse forwarded at this meeting. The Health Nurse informed me verbally that almost all of the participants listed had requested to be interviewed. Both she and other members of the Health Committee had spoken with a variety of individuals from the community about this possible project. The feedback they received was that many

community members were very interested in participating and sharing their insights.

Information regarding the proposed content of the interviews was forwarded in writing to Chief and Council. In addition Chief and Council were informed as to what cross section of community members would be interviewed (parents, parents of children with disabilities, Elders, teachers, social development workers etc.). Written approval from Chief and Council to proceed was given October 7th, 1991.

The interviewer was invited to present a summary report of the data to Chief and Council four months after the interviews were completed. In addition, a written report, summarizing the findings of the study, was given to Chief and Council. The community did not feel it necessary to review the transcripts of the interviews as they felt that this might compromise the confidentiality of the participants.

Data Collection

Research information was gathered primarily through in-depth interviews. The focus of the interviews was the perceived needs of children with developmental delay, or at risk for delay, and the related needs of their families or caregivers.

Participant Selection

Originally, eleven participants representing a cross section of the community were selected from a list of those volunteering to be interviewed. As the project progressed two interviewees were unable to continue their participation. On two occasions one participant, a parent of a child with developmental disabilities, was unable to participate in the interview because she was intoxicated. On one occasion a social development worker, was not able to participate because she had a scheduling conflict. Of the nine interviewees who completed the interview process, six were females and three were males.

Participants are not referred to by their real names. Pseudonyms have been used.

Participants:

May: May is female Elder of the community. She is also Jean's mother-in-law. May married in 1936 and came to live and raise a family on this reserve. She has six children, 5 boys and 1 girl. She also lost three children in infancy. She and her husband farmed and raised livestock on this reserve. She now has many grandchildren and may soon have some

great grandchildren. Children have been very important to her throughout her life. She would often take care of other children in the community as well as her own. May lives with her son and Jean.

In the Indian culture it is a sign of respect to offer Elders a gift such as tobacco. For my interview with May I brought her some tobacco which she seemed to appreciate.

Sue: Sue is a parent. She has one child with developmental delay, an infant, and other school aged children. Sue has had a fair amount of involvement with services for her developmentally delayed son. At the time of the interview she was receiving home-based early intervention services from a larger community approximately two hours drive from the community. Sue and her family live in a more isolated area of the community. The nearest neighbour is approximately a quarter of a mile away. Sue is not originally from the community. She has been living in the community for approximately four years. In Sue's home I noticed many religious sayings and pictures on the wall.

Jean: Jean is a parent and also the administrator for the community. Her daughter is a twin (her twin sibling died at six months of age), is developmentally delayed. She too has had a lot of experience with services for children. Jean was receiving services from the early intervention program; however, her daughter was discharged from the program because of developmental gain. Jean felt that they discharged her too soon. Jean's husband does much of the child care. Jean is not originally from the community. Her husband is also very involved in the community and is the Chairman of the Health Committee. Jean and her family live right at the edge of the community. The family owns land outside the community which it still farms.

Paula: Paula at the time of the interview was a Social Development Worker for the community. She is from the community and has a family. Our interview did not take place in her home, rather at the Band Office. Paula did not seem comfortable discussing any personal experiences, rather related most of her comments to her professional involvement with the community.

Liz: Liz is the kindergarten teacher at the community school. She is from the community, has children and is the income earner for her family. She and her family live in a section of the community where there is a cluster of approximately six homes. Our interview took place in an empty office space in the school. Liz made a point of showing me the school and introducing me to some of the younger students.

Donna: Donna is a primary teacher in the community school. She does not live in the community, rather commutes from the neighbouring community, which is also her home community. She is Metis. She has been teaching in the school for a few years. Towards the end of my study I was told that Donna would be resigning after the end of the school year. She was moving to Edmonton to further her studies in the area of counselling battered women.

Rick: Rick is a male Elder in the community. He and his wife continue to try to follow traditional ways in their everyday lives. They smoke their own meat, have younger family members hunt for them, and eat

many of the more traditional foods. Rick is quite fluent in English, however his wife chooses to speak primarily in her native tongue. Both Rick and his wife are very involved with their family and young people in the community. They have some of their grandchildren living with them. Rick enjoys and values humour. During our interview he was wearing a cap which read "I'm not old, I'm just a recycled teenager".

Steve: Steve is from the community. He and his wife have lived there all their lives and have raised many children, both their own and others which they took into their home over the years. Their children are now teenagers and adults. The teenage children go to school in the neighbouring community. Steve is very involved with his community. He is the chairman of the community school committee. He is quite concerned about raising the quality of education in the community and increasing community participation.

Bob: Bob is the principal of the community school. He is also a parent of a child with developmental

delay. Bob is originally from another reserve community and has only been in the study community for less than a year. He has been a principal of other reserve schools for a number of years.

The Health Committee Chairman seemed quite comfortable with allowing individuals to come forward as the project progressed and did not request prior approval.

All participants had the choice of having the interviews tape-recorded or not. My preference was to have all interviews tape-recorded, however, not at the expense of intimidating a participant or making him or her uncomfortable. All tape-recorded data were transcribed. Once the project is completed all tapes will be erased. Five interviews were tape-recorded. For those who chose not to be taped, notes of participant's responses were made immediately following the interviews. In order to help interviewees feel at ease, no notes were taken during the interviews. Each person was guaranteed anonymity and confidentiality of their responses.

Interviews

Interviews were semi-structured. This format was chosen to allow for an open-ended dialogue to encourage as much individuality in responses as possible, as well as ensuring that similar topics were covered with each participant. Spradely's typology (Spradely, 1979) was used to guide the interview protocol. This typology includes three major groups of questions:

- (1) descriptive - how the individual sees his/her self in his/her setting
- (2) structural - the concepts (constructs) the individual uses to depict his world
- (3) contrast - the relationships between concepts.

The interviewer raised specific topics, but allowed interviewees to discuss them as they felt comfortable. The topics raised included:

- (1) Observations of young children's involvement and place in the community
- (2) Who do children primarily interact with and which interactions did participants see as being important for the children's growth and development?

- (3) Participant's awareness of children with handicaps and what does the word "handicap" mean to participants?
- (4) Did participants feel that the above issues differed for a child with a handicap?
- (5) Insights into existing services. What services each person would like to change - add - delete?
- (6) Would participants like to be involved in planning services, and if so in what way?
- (7) How is the community presently involved and what level of participation would be desirable?

This list was a guideline not intended to exclude other points which participants made during the interviews.

It was suggested by the Health Committee that I be accompanied by Val, a member of the Health Committee, to each of the interviews. She could also act as interpreter if requested by a participant. Val generally made an introduction to each participant prior to the interview. Her presence was perhaps also a gesture to indicate that the community supported this study. On only one occasion, in Sue's home, were the initial introductions done in the communities native language.

Sue indicated that she would prefer to speak in English and that interpretation was not necessary. The interviews were held either in participants' homes, or in some cases at their place of employment. Each interview lasted between one to two hours. A total of five visits were made to the community to gather all the data.

Field Notes

The contents of the field notes are both descriptive and reflective. The interview setting, interviewees and their actions are described. The reflective information includes my impressions, frame of mind, ideas and concerns. The intent of the field notes is to help identify possible ethical dilemmas and conflicts or prejudices which may arise during the data gathering. Field notes were written directly following each interview.

Data Analysis

A constant comparative model (Bogan and Biklen, 1982) for data analysis is used in this study. This model allows for interplay between data organization and

analysis, where the analysis guides the direction of the data organization. The constant comparative model involves collecting the data, reviewing the data to look for recurrent themes or categories of focus, organizing the data around the designated categories of focus, describing the categories and developing an emerging model (Bogdan and Biklin, 1982).

An audit trail was established to facilitate the review of the process of the study. This helped to link the data collected, audio tapes, transcripts, field notes, and coding of transcripts. It was intended to demonstrate how I moved from one step in the analysis process to the next. The auditor was my supervisor, Dr. Barbara Bloom.

Ethical Considerations

Ethics refers to the principles of right and wrong which a particular group or individual chooses to accept (Bogdan and Biklen, 1982). The two dominant issues in the ethics of any research are, informed consent and the protection of the participant from harm (Bogdan and Biklen, 1982). The participants must therefore know that they are entering the project voluntarily and have a

clear understanding of the nature of the study. By agreeing to participate they are not exposing themselves to any risks which might be greater than the gains they could receive. A consent form, to be signed by each participant, was designed to take into account these ethical considerations. I offered to have the consent form translated into the language of the people of the community and the participants would have the choice of signing either of the two versions.

The Health Committee however felt that given the way in which things are done in their community presenting participants with a form to sign would not be well received, and perhaps might be misinterpreted. The community values a less formal way of doing things and prefers verbal agreements. I therefore presented the same material verbally to each participant prior to their consent to be interviewed.

Confidentiality is a key ethical consideration. As well, confidentiality is closely related to providing protection for the participants. In this study, each participant is the owner of his or her data. Participants were informed that each may withdraw from the study at any time. If they chose to leave the study each individual would take his/her data with them. At

the end of the study all audio tapes will be erased. In addition, the study did not use the proper names of the participants, nor was the study community or other communities referred to by their proper names.

Limitations

The cultural difference between myself and the participants might have affected the study. I tried to generate additional insights into the nature of the social life of the study community by increasing my knowledge of the setting. I did this through reading and discussion with Indian people from outside the community, prior to doing the study. I am aware that I may have been perceived by some participants as an outsider, perhaps with a "hidden agenda". Perhaps my intentions were questioned, though this was not communicated to me in any way. However, to say that one person from one culture cannot interact in a meaningful way with individuals from another culture is cultural "apartheid" (segregation and discrimination). Listening and learning are key elements in forming the basis for cross-cultural research (Haig-Brown, 1989).

Language might possibly be another limitation in

this study. All interviews were conducted in English. All participants were asked if they felt comfortable conducting the interviews in English. For those participants who were not comfortable speaking English, arrangements were offered for an interpreter from the community to be present. Participants preferred to speak English, however, and did not wish to have an interpreter present. This was also the case for the Elders who participated in the interviews.

In conversations with the Health Nurse and other members of the Health Committee, I was given the impression that English is the language generally used in the community. There are only a few Elders who still speak the native language. Comments from participants also alluded to the fact that it would be to the communities benefit to encourage the younger generation to rediscover their native language and heritage.

CHAPTER FOUR

RESULTS

The results portion of this document is a summary of the themes of meaning which emerged from individual participants' interviews at the study site. The data presented are categorized by themes and subthemes. The author's interpretation is presented along with those edited quotes which best illustrate these themes. A participant's name followed by (:) indicates quotes from participants who were tape recorded. Non-tape recorded information is presented in the form of a summary of the participant's responses.

In order to maintain the anonymity of study participants, the author has not included the unedited transcripts in the thesis document.

Editing procedures have been carried out for clarity and ease of reading. Spoken language is very different from written language. An interview is primarily a spoken dialogue between two individuals. In this format, the speaker often uses nonverbal cues which allow the listener to better understand the information presented. The editing for this thesis includes additional information in parenthesis to make the

written transcripts of these spoken dialogues more comprehensible. This added information is intended to make the non-verbal cues of the dialogue apparent to the reader. As well, information in the dialogues not relevant to the topic, has been omitted and is indicated by the use of (...). Names of individuals and places have been altered in both the unedited and edited transcripts.

CONCERN FOR THE WELL-BEING OF ALL CHILDREN

Concern regarding the well-being of all children in the community, not just those with special needs, was expressed by all participants at some time during their interview.

When asked what May would like to see for children like her granddaughter (who is developmentally delayed) she said that she would like to see all children cared for. There are many children who are far worse off than her granddaughter because they have no real home or anyone to care for them. These are the children she is most worried about.

Liz: Under the age of five,... a lot of these kids that aren't in school yet you always see them outside. You never see them inside doing something with their parents or anything like that. I don't see very many parents working with their kids to tell you the truth. They just leave them alone.

In addition, a feeling shared by all participants was that they saw the children of the community as their most valued resource.

Liz: The little ones are tomorrow's leaders. If they're not going to help more of them, my goodness most of our future leaders are going to be in and out of jail and lord knows what. Something has to be done.

Bob: The community is no different than any other community that I have been in. Their main concern are the children, especially on reserves with Native people, always children. You know, your children are your future and that's like, we ... even in non-native communities same thing. The children are their future, even if they are a small rural farm community. The children are their future...

Concerns about Parenting Skills

Concerns were expressed regarding parenting skills and a lack of good parenting models for young parents.

I tried to focus the conversation on children below school age. For these children Rick felt parenting, or lack of, is the biggest problem. Because of the parents ignorance they are having children born with problems, (effects of maternal alcohol abuse) or having children that aren't really wanted.

Paula identified issues around

caregiving. One issue which she talked about was poor parenting skills. Sometimes this is family specific where one generation has the problem and because of lack of appropriate parenting models it is passed on to the next generation. Other families are doing okay and they are the ones who have good things to pass on.

Jean identified a lack of parental awareness of what parenting supports they need ...She made the statement "I don't know why some people refuse to accept their responsibility as parents...Maybe they don't have good models. Maybe they're afraid to go with their gut feelings. Somedays I survived because of my gut feelings. I did what felt right to me".

Possible Explanations for Inadequate or Lack of Parenting Skills on the Parts of Some Parents:

Participants discussed various explanations for inadequate, or lack of parenting skills, among some members of their community. These explanations seem to fit into three main categories; (1) residential schooling, (2) lack of confidence and pride in oneself, and (3) feeling caught between two cultures.

1) Residential schooling

May feels that the era of residential school was very harmful to the idea of family. Kids who left home very young never got the benefit of learning about parenting by watching their parents be parents. Many of the old traditions and ways were lost and not passed on from

one generation to the next. Children who were raised in residential schools lack Indian parenting models, or parenting models altogether. When these children became adults, they either lacked or had inappropriate parenting skills, and therefore failed their children, who are now parents themselves lacking those skills. She also spoke about the traditional role of the Kookum (grandmother) and how she sees a whole generation of Kookums lost because they were never shown the ways of child rearing. May felt that the young mothers of today have no one to show them, guide them, or keep them interested in being mothers. She attributes this lack of guidance to the fact that their mothers were part of the residentially reared children.

For May the Catholic faith has been a big part of her life. She taught Catholicism to all of her children. She feels it is important for people to believe and be guided. Too many young people have no guidance because their parents had no guidance. She believes the residential schools were not Christian in their approach and provided little support for those children to adopt Christian ways. The Christian doctrine, accepting others as they are and treating everyone fairly, with love, was not practiced by those who taught in the schools.

2) Lack of confidence and pride in oneself

Liz: ... Maybe it's the parents that need help first. The kids we try and help them here (school). But maybe it's the parents who need some kind of confidence, ... to know they're out there.

Donna: In the depression people had kids. They had twelve kids. They didn't have Social Services or anything like that. A lot of these people (today) are handed stuff. They don't feel they have

to go out and do anything. A lot is given to them. I think they have to, I don't know, I just feel that if they (the parents) got support to help them with their self esteem they could be what they want.

3) Feeling caught between two cultures

Rick spoke about how young people today do not know enough about their roots and therefore don't have much pride in who they are or where they come from. Many traditions have been lost. People are not sure what should be passed on from generation to generation. "When you are always taught by white people their way and how they see the world you start to feel your way must be wrong or not as good." He continued to speak about how young people are more influenced by the outside culture than the native way. Their role models are not Indian. At the same time some young people are beginning to show some renewed interest in exploring some of the old traditions. It is more the young in school who are asking questions about their heritage, the young adults and teenagers are still wandering.

Paula talked about those families who were lucky enough to have family members who passed down some of the traditional ways. She felt that it is these families who are better able to cope with the pressures of their situation. She sees many young and not so young people in the community who seem to be caught between two cultures. TV and the media in general, has a significant influence on young people and their developing identity. She also finds that it is sometimes opportunistic to be Indian and other times to seem more white, to make the system work for you. "When an outside culture controls the system you learn how to make it work".

Accepting Parental Responsibilities:

Participants saw that it was difficult for some community members to accept their responsibility as parents. Some participants felt the reason for this may be more a lack of knowledge and understanding, and that parents needed support in this area.

Liz: ... A lot of these parents... that are being absent parents are probably feeling neglected themselves... 'cause there's just no mom ... in almost all the cases... If you're being neglected I would say you're sure not gonna think of a way to demonstrate (love) to kids when they're feeling pretty low. I don't know, I think ... eventually somebody is gonna, have to talk to them.

Steve: Something (parental commitment and responsibility) that's needed on the reserve so parents can also understand... It's no use to just work on the child without working with the parents. They (the parents) are not left out purposefully, but they have to be able to understand their help is needed.

Steve: For me that would be great, just great (intervention support). Cause the parents need it too, not just the child. They have to understand that (they have responsibilities) when they have a child. What problem the child has got. They have to understand that. That's the same a lot of times ... that's the same for all the children in the school. The parents have to be educated, too; in some way that they understand that their children need education. A lot of parents don't seem to, I don't know if it's that they don't care or that they're just negligent about it, the education program, even the regular education program. I don't just mean the children that need special assistance. You know you have children that don't come to school and the parents aren't strict enough to send their child to

school. If their child doesn't want to go to school then they just keep them at home which is not good for your child. They're gonna grow up and what's going to happen later on. Some just aren't strict enough. You don't have to do it today, well you don't have to. That's the same thing with the society on the reserve. They don't seem to think that it's important enough that you respect other people.

Steve provided a personal experience to demonstrate what happens when responsibility for caregiving is not accepted on the part of the parents.

Steve: ... parenting on the reserve is pretty hard for some people. Many people... it is not possible for them. Years ago these children that we had are grown up now. But two of them (children that they took in) didn't turn out so good. The rest of them seem not to have too many problems. What really happened there is ... That's quite a few years ago, when the residential school was in operation and we went there some summer at the end of June and all the students were gone. There was a little boy sitting on the steps. He was being looked after; he had a place to sleep; had his meals and so on; but nobody picked him up. The parents were separated and the grandparents didn't want to bother. They were in Alberta. So the school asked if we would take him home. I really didn't know what to do because this child was really wanting to come home, back to the reserve. So we decided to take him and keep him -til the grandparents came back from Alberta. When the grandparents came back it was about the middle of July. Already towards the end of July. We brought him back to their place and they said that if we wanted to keep him we could keep

him. So we were stuck with him (little laugh) all summer. So the next fall, the next school term, he didn't want to go back to Onion Lake (residential school). So we decided to keep him here and send him to school in (neighboring community). So this kept going on and we ended up keeping him till he was 16. The Brothers at the school wanted him back. We told them that he said he just wanted to come home. The parents were separated. The grandparents were getting around (were very transient), and after that they said they didn't want him anymore. Well if you're willing to keep him, then keep him. So we kept him for those years. Then his brother came to stay with us. We ended up keeping him, too; and there were more that came after that. We had six of our own at home, then. We ended up with eleven. But we managed. Two come and visit us once in a while, but not all.

Care Giving for Children Under the Age of Five Years.

Older Children Caring For Younger Children.

The way in which young children spend their time and with whom varies from one family to the next. Participants tended to discuss those children and families about whom they had the most concern. There was a general feeling that there are a number of very young children in the community who spend a significant amount of time on their own, generally outdoors with limited or no adult supervision.

It is not uncommon in some families for older siblings, rather than adults, to be responsible for the

younger children. Repeatedly, concern was expressed for these children who lack supervision or have inappropriate supervision, and are thus seen as very vulnerable.

Liz:... There's so many kids that are left by themselves, for days on end... And the oldest... some are lucky if they have someone over sixteen. But most are younger than sixteen that are home, that have to look after these little ones, send them to school and what not. And believe me I've reported it, how many times when I've known these kids to be alone.

Donna: ... I have to say the children are very protective over each other. Big kids look after little kids. If mom isn't able to do it the oldest one will stay home. It doesn't matter if she's in grade three or five, she will make sure that the little one is looked after, fed or whatever. They really look after each other. The kids just stick together like glue.

Donna: The responsibilities of some of these children is phenomenal. They're only kids themselves and they've got to look after the little ones.

Donna: They protect each other. I find that even in school here that if one child doesn't come with a lunch it's nothing to ask the children to share. There's no problem, they all share.

Effects of Alcohol on Caregiving Responsibilities

Some of the participants made reference to alcohol and its debilitating effects on both the individual and the ability to respond to the role as parent. Liz's

description of what she observes repeatedly in her area of the community, is a concern that other participants alluded to as well, but not to the same degree.

Liz: But there is such an overwhelming power of bingo mania here right now (she chuckles). It isn't bad. You can go to bingo. But the one really bad downfall is liquor. In the east end, kids are growing up parentless for so many days on end because of liquor,... having to end up with Kookum (grandmother) who's sick and can't really look after you. How else are you going to grow up, but feeling bad and neglected?

Liz: ... and a big factor for moms not being home is that they've broken up with the dads. They've gone their separate ways. They're drinking to get over him or whatnot. But those are such flimsy excuses...I find them as flimsy. Maybe I'm being a real prejudiced person against liquor, because I don't drink; but these are just self-pitying excuses. And if there is so much pity in the parent, how is she going to be able to work with her children? They (the mothers she describes above) need somebody that's going to show them that they care about her and her family. But nobody checks up on her. I wish the welfare people would do something. It's only been about a hundred times I've told them about these things. Nobody's ever done anything. I've never seen anybody go there. And, you know, it scares me cause we live right near there and me and my husband don't drink, and we're home on weekends. What scares us is these kids walking back and forth, back and forth, from one house to the other. Because nobody's home and the oldest is eleven. And I said to my husband "you grew up like this here". He knows now. He's 39 but he knows now what... He had had a very troubled life. He quit school early, and he says the

same thing is going to happen to these kids if nobody watches them. You think anybody is going to listen to us now? We told the moms of these families to look after the little ones but they just ignore.

Primary Caregivers

Caregiving does vary from one family to the next. Who looks after the children often changes from one day to the next. It is common for grandparents to assume a significant amount of caregiving responsibilities within the community. Members of the extended family may contribute to childcare as well.

Sue: I do (provide caregiving). Moms... Not with me (other family members as caregivers), I do. He (her son) doesn't do good when he's with others... No (no time away from children), I stay home all the time.

Bob: Other than that, they (children)... are more or less at home with their grandmother or grandfather what we call Kookum or Shookum. Or else they're with their mother, or aunties, or baby-sitter, or whatever may be, depending on the parents, if they're working, and it's in a home setting. It's a very close home setting... the extended family, their way of life, and the children will be tended to by their immediate family and the immediate family may consist of several members.

Liz: Well there's, I live on the east end and that's where the (A's) live and the (B's) and the (C's) and the (D's), and all four families... those kids have grown up with grandparents, or uncles. The moms are never very stationary. They are there for a few days and then they

go off drinking again. That's where a lot of what I was talking about comes from.

Steve: That's I think, the grandparents that are there, get stuck with the children. With both parents or single parents it's still the grandparents that look after the children. Why is it? I don't know, because a few years ago it wasn't that way.

One of the male participants took on the responsibility of the primary caregiver in his family. He was also the son of one of the female participants.

May said that her son does a lot of the caregiving in their family. He came home towards the end of our discussion. When he first came in she became quieter. He asked how we were doing. I said we were having a nice chat. He looked in her direction, gave her a wink and told her to go on and continue chatting. She gave him a very warm smile back. He preceded to put the youngest child down for his nap and gave the four year old some milk. He then began preparing what might have been supper. He was boiling chicken and preparing potatoes.

Need for Respite.

For parents and caregivers of children with disabilities the need for respite support, the opportunity to get a break, was identified as needed but unfortunately lacking. Since much of the caregiving responsibilities tend to lie on the shoulders of the parents, particularly the mothers, it is difficult for them to ever get a break, or

even go into town and socialize. Isolation for both the parent and the child was seen as a concern.

Jean talked about parents need for a break. "If I didn't have the home environment and support (her extended family), I don't know where I or the kids would have ended up."

Jean (who has a child with a disability) saw home visits as a break, a visitor coming to the house. "Friends are afraid to visit, at first. Maybe they don't know what to say"... She identified how important and necessary it was to get a break. People forget that you need to get away. Too much stress... too many directions to have to go in... can lead to potential abuse. Sometimes you feel stressed and overloaded with kids, period. But it's 100 times greater if you never get a break from the special needs child (the child with a disability) and the situation.

Steve: I believe that that's a possible thing (giving respite support). That it's a very difficult thing they (the parents) are doing, looking after them day after day. They get frustrated. The problem is you have to have money for that.

Sue:... He doesn't do good when he's with others... No (no respite help) I stay home all the time.... Okay (pause then a slight, shy smile). I guess I should get a break too (silence for a fair stretch). Ya, he runs inside a lot and climbs. It'd be good if he had a nursery school (silence)... Ya, (nursery school could be used as respite) (silence). Maybe he'll go to the class at the school (preschool class)... Ya. They have to be 4. It's Rose's class. It's two days a week, all day (silence). I think he'd just go mornings.

(Observations during the interview with Sue)... Her son is a real climber and can get to just about everything, including knives which he pulled out twice. He was also into drinking anything that could be poured, including the dishwasher in the sink. Sue was up and down a lot. Her manner never changed. She just calmly took potentially dangerous objects away from him. He accepted this and would just move onto the next thing. After approximately 30 minutes he moved into another room. When Sue could not hear him she went to check to make sure he was all right. During the entire time her baby remained in her arms...She stated that this was fairly typical of his (the four year old's) daily behaviour.

Val commented as we left Sue's house "No wonder I never see her around. Everyone says she just stays at home."

How Children Under Five Spend Their Day

Location of Family Home

Location of the family home was seen as a factor governing how young children spend their day. Children from families who are more isolated geographically, tend to spend less time playing with other children, especially when their siblings are in school.

Bob: ... For example, here we're close to what is considered the development of a small village in the reserve... there are a few homes... there's three or four homes that are very close together. Consequently the children do intermingle and play with each other... usually

(there is) a little bit of fighting... Territorial ground and so forth is distinguished ... they recognize that (territorial ground) and they play within those areas but they're ...inclined to be more indoors. But if they do have a nice day ... you will notice quite a few little tikes playing around outside...

Sue: My 4 year old can't be outside (points to latch on door). He goes down the ravine so I keep him inside most of the time.

Sue: There are only two houses around here. Some parts of the reserve have more houses closer together so there are more kids to play with. He watches lots of T.V.

Limited Interactions Between Adults and Children, Neglect.

Limited interactions between adults and children was a concern which continued to come out in many of the comments made by participants. They felt that the limited interactions at times border on neglect and deprivation. Though the other participants expressed their concerns, Liz spoke most openly about her observations of neglect and deprivation.

Liz: A lot of these kids here grow up with not having their parents here. It's sad. They come to school and spend time with the same person every day and that person is praising them and you know really trying to... We try and spend some time with each and every kid. Even if they do just a little bit, we really give 'em a lot of praise. Some of them are just amazed. They've never gotten anything like that. The attention they

get at school and the non-existing attention they get at home I think is really conflicting in these children... I guess they get all mixed up. See here we're building up their self ego or their self confidence. They go home. Nobody's home. And if they have work to take home to show their parents and there's nobody home, I could just imagine the feeling... destroy the good feeling just washing right out of them, you know.... When you're giving instruction to the older ones you have to use your arms a lot and if one of them is close to where your arms are swinging, you should see the faces on some of these kids. Sometimes they come in hungry. You ask them where mommy or daddy are. They don't know, or they answer "she run away" or "she's drunk" or something like that. There's been quite a few... I don't know how many... There's about three, four FAS children in those families. Two are from one family and the mother, God help me I could strangle her sometimes, she never stays home. It's the grandma that looks after them. But the grandma, she's never well. She's got a really bad case of diabetes and she's still got to look after these five kids... Help them... So there's five, and two of them are FAS children. One is really bad. She's here in school now... How much attention can a grandma who's not feeling well give to these little ones? She can't teach them. In her days she probably taught her kids how to clean house, bake bannock. But today when she's got five little ones to look after, where's the strength to show them, you know, real life skills? The other ones, pretty long a year ago... With them it was the same story. They didn't have a mother, they had an old grandmother there. It was her mind that started going funny. I don't know. There wasn't much she could do... and there were little ones. It's really really bad... those are the ones that I have reported again, and they (the community)

haven't done anything. Nothing yet. I don't know what they're waiting for, before they do step in and try and do something... I think they (the parents) neglect kids. Don't do anything. Oh when they come to school, they (the children) are the ones that are so eager to try and please you. They are forever trying to seek praise. At first they were so scared to do anything but once they start seeing the other kids getting praise for what they'd done, you should see them just really trying their hardest. One little praise and a pat on the head or back, oh, it goes right to their head. It's like you got a brand new toy, you know. We've gotten around to giving our kids a hug. Oh God, you should see some of them. You know these little ones that I know have it bad. They never got that (hugs) from home. It's really easy (to give kids some attention) you know. The Social Services, they don't do anything. Who will?

Liz: Let me tell you my husband had a grade six. Ever since he's been sixteen he's been in and out of jail. And when he was out he was out drinking, stealing drugs, he used to be dealing drugs. He'd kill me if he heard me say that (a little laugh). We talk about it now, and he knows that his mom's ways were all wrong... The mistakes his mother made when they were growing up. If they had had (guidance). Like the little ones that I was describing. (At this point she refers back to her husband and his siblings) They were outside doing this and that and what not... That's what they did. They grew up being a thief, drinking, they were like... What you call them... It took him ten years to realize the problems were his own.

On the one hand participants expressed the need for children to be with other children, yet also felt that

adults should play a major role in guiding and teaching children. To do this they saw it necessary for adults to spend time with their children. Spending time with them would also help the adults better appreciate and understand the needs of their children. Everyday opportunities such as taking children shopping, on errands were identified as missed opportunities. Without care, attention and experiences, it was felt that children lack the opportunities to develop confidence in themselves and a sense of well being.

Liz: They (the kids) help you, you know they (the kids) watch them (the parents). If you're cleaning up in the morning ... that's when there are those educational things to learn. Even if it's only one (time)... it helps every little bit. But a lot of them just get sent out, or they prefer to do things inside or what ever.

Steve: ... To talk from my own experience. My children were always home. One of us was always home. (Steve and his wife were always aware of where his children were). We played ball: They never went out by themselves because we didn't let them. You play with them. That's all it is. You don't have to do too much. They work with you until they are grown. But now you see... they (the parents) don't want to stay around. The grandparents are left with the child. They (grandparents) seem to feel that they are responsible... They are responsible if they look after the child. I don't understand why it's come to be that way, because it never was that way before.

Donna: ... Routine seems to be lacking.... I think a lot of the children spend a lot of time by themselves. Outside lots. I don't think... I don't think they spend a lot of time on education. Doing things at home. Coloring books. They miss a lot of that. They spend a lot of time outside by themselves, entertaining themselves, just building forts and doing things like that.

Liz: ... Whoever is home keeps the kids... Or else if nobody's home (no adult or older sibling), they're (the young children) at someone else's house... I don't think that (it) should be very hard to take them (the children) with you wherever you go. Spend time with them... It's a big treat for them (kids) to go into a store... My two year old and my four year old they love going shopping with me ... They have these little miniature carts there now. And then they get to shop too and it gives them a feeling of better self worth maybe. So a lot of these kids here never get to see town. And town is only, what, a few miles away. That is something that always bugs me. I never see these parents trying to spend some time with the little ones, now that they have the time to spend with them... The older ones now are in school. There is none of that (time spent with kids). And with these FAS (children)... There is quite a few of these FAS children on this reserve that should have daily... The parents working with them daily. But there is none of that... A lot of these kids are badly neglected even though the parents are home...

Transience

Families moving from one community to another, not establishing roots was a concern of Donna's. She felt

that this type of transience prevented children from developing a sense of who they are and how they fit into both their family and the community. In addition it prevents them from developing a sense of commitment to see things through.

Donna: Some days you (the caregiver) might have 8 kids at home. Next day only one. Next day you might have ten. (Because the kids don't feel like going to school). They might be here on the reserve but they're still not in their home base (their home community)... Yes, a lot of the school age kids just... The school age kids register here (at the school) maybe two or three times a year. Leave. Come back. Leave. Come back. (They) might stay home because they don't feel good anymore. They leave for awhile. Come back. They don't feel like they really belong to anyone or anywhere. They also learn to leave when things get tough. Just like their parents.

Individuals With Whom Children Spend Most of Their Time.

The individuals with whom children spend most of their time varies. As mentioned previously, children are often seen primarily with other children with limited or no adult supervision regardless of their age. However, other children may be with one adult and no other children. The latter seems to be more typical for children with disabilities.

- 1) Other children, limited or no adult supervision

Liz: (Children spend most of their time) with their peers, because they are the only ones that are home during the day. Peers or younger. The other (children) that are there or whatever.

Sue, a parent of a child with disabilities, felt that there is limited opportunities for her child to interact in the community prior to entering school.

2) Child with special needs, primarily in home with mother

Sue is a very quiet person. During the entire session the 4 year old got into just about everything (very active). Sue had her 11 month old in her arms and quietly and calmly dealt with the 4 year old. She always had one eye on him to make sure he didn't do himself any harm. He is a real climber and can get to just about everything, including knives which he pulled out twice. He was also into drinking anything that could be poured, including the dishwasher in the sink. Sue was up and down a lot. Her manner never changed. She just calmly took potentially dangerous objects away from him. He accepted this and would just move onto the next thing. After approximately 30 minutes he moved into another room. When Sue could not hear him she went to check to make sure he was alright. During the entire time her baby remained in her arms...She stated that this was fairly typical of his (the four year old's) daily behaviour. She is at home all the time with the two during the day and then the six of them (her other children) after school. She is reluctant to take her son to community events or out because others laugh at him or fight with him and he likes to fight. They (other children) run away because they don't understand why he does what he does. As a result she herself rarely goes out.

Sue is very involved and aware of her children and what they are doing. She responded to all situations whether it was the four year old getting into something or the 11 month old fussing.

Paula stated that children with handicaps are difficult to identify because they are mostly in the homes.

School Aged Children and Services

Choice of Schools

In this community there are presently two choices for elementary schooling, the Band School on the Reserve and an elementary school in the neighboring community (approximately 15 minute drive away).

Participants identified strengths and weaknesses with both options based primarily on their personal experiences. In general, individuals have different opinions concerning the educational needs of their children and what educational facility could best meet these needs. Steve for example was of the opinion that attending the Band School limited children's opportunity for extra curricular activities such as sports.

1) School in neighboring community

Steve: [There is a school in the neighboring community. Some residents of the Reserve wanted their own school built. In this excerpt Steve shares his observations as to why the school (on the Reserve) was built, and some of his

feelings around this]. I think it helped (having a school in the neighboring community)... The people there (in the neighbouring community school) are pretty sensitive I think.. In ways... it can take more, more than a Native person (to understand how to support and help the kids from the reserve). Going to school in (the neighbouring community) the Indian children, the Native children... A lot of them enjoyed it. But...what happened when they wanted the school built on the reserve was... There were about 3 or 4 families that had problems in the (neighbouring community) school and they,... started this, wanting a school on the reserve. I had my children go to (the neighbouring community) school. They went. I believed that the other things from school were important too. They went to figure skating and hockey. My children were in there. They were accepted. There were times that we had little problems like...I think we had one of the girls ... I can always remember that one (his daughter) went to school one day. We thought one of the teachers was being mean to her. So we talked. I went to the principal and asked about the teacher. And he explained to me why it was that she (the teacher) was mean... She (his daughter) had gone to town without asking. She understood she was wrong. If I had gone to the principal and said you're not treating my children right... where would I be? I'd be the same as the other ones (other parents) and I'd have to take my children out.

2) Band School

Individuals who favoured the Band School expressed some suggestions for improvements but generally felt that for the elementary years, the children were being

better served within the community. The Band School has more potential to reflect the cultural background of the students and incorporate it into the curriculum.

Donna: ... I don't really know (why kids go to neighboring community school). I think some (reasons) might be political. Not wanting (schooling) from the Reserve. Some might be political but... most of them (children from the Reserve) come here. I don't know how many (Reserve) children we have in (neighboring community). Someone mentioned the number fifteen. But I could be wrong. Some of them also live closer too, right in town... They don't bus the Native children from (outside Reserve) to here... They (residents of the Reserve) have the choice yes... Maybe because of living-wise they (some Reserve residents) take them to (neighboring community)... Maybe the parents of these children... A lot of them are in job situations like, RCMP... She has a lot to deal in the community outside of (Reserve). (Also) our lawyer who deals a lot with outside the Reserve.

Val: ... That's just the way it used to be. I guess not everybody gets along here and some parents want their kids to go to school in (neighboring community). (silence). More and more kids now go to school here (looks to Sue for acknowledgement).

Integration of Children with Disabilities

Integration of school aged children with disabilities, especially into the primary grades, was seen as valuable by the participants. The major concern expressed by a family member of a child with

developmental delay, was that of her child fitting in with the other students and not being laughed at. This concern was not raised by the other participants. Instead they felt that the more visible children with disabilities are in the community, the more accepted they would be.

Sue: Ya (her four year old will go to school on reserve). Maybe (in) a special class in the school to teach him to speak (silence). He understands, he doesn't speak. He learns what order things go in. When I make bannock, he knows when to bring me the water.

Sue: I want to see him (her son) with the other kids. They laugh at him but they'll get used to him. When he can speak maybe they won't laugh or tease him as much. (silence) All my kids now go to school on reserve.

Donna: ... I feel that if Jane (child with visual impairment and developmental delay) had been a child or someone maybe in the (neighboring) community, or just outside the Reserve, the instinct might have been panic, fear. But they (her parents) dealt very well at home and educated her really good and she came here (Band School)... She is still the same and she was never looked upon as a problem...

Bob: ... I have learned that what applies to the ground level in regards to special needs children, is that everyone is special in their own way, and everyone's needs must be met in a different way. You must identify with that child's welfare and where they are, within that classroom. They must learn to coordinate themselves and work with others but at the same time they must

work at their level... Let them (special needs pupil) achieve first so don't give them a structured program. Maybe give them a modified program.... I'm a firm believer; work with the child to assure the child that you're there, but let the child move out and advance into other groups... That's what's happening quite well and quite successfully with the two that we have here (in the Band School).

Bob: The one thing with Jody (a child with visual impairment and developmental delay) is the one school she was ... they really tried to incorporate (integrate) Jody... It was very difficult for Jody because she was taken away from her home in order for her to attend that school (off the Reserve). I think that's where they (the school) had real problems... Jody didn't want to be involved... Now that we have her here they (education consultants) were quite surprised when they stopped in here one day... (We, the school staff) told them she is in phys.ed. She does this. She does that... Her attention span is not going to be the same as a child in grade three but she still participates. If it's only for ten minutes I'm happy.

Elements Identified for Growing and Learning.

Participants expressed a variety of different opinions in this area, however, they all shared in the opinion that children need to feel that they belong, and that people are good to them. The understanding that children can count on someone to care for them and nurture them was foremost in the participants' discussion. These two elements were seen as important

for young children in order to help them develop self-esteem and confidence.

Children Need to Feel That They Belong

- 1) Children can count on others to be there for them, love and care for them.

When asked what were the most important things for growing children May said, being good to them. A child always knows when you are being good to them and they will come back to you. Children need to be cared for and feel loved.

Liz: The most important ingredient they (the children) need is not there. It's that feeling, the feeling of being wanted and loved. Because without those how are you gonna grow up to be something... a person?

Liz: If you want freedom... There always will be freedom for you... All these little ones need..., just half an hour of your day... To do something with their kid. Just to make'em feel... they're there. I don't know,.... make'em feel like; hey I'm here; I'm noticed; Mommy loves me... Can you imagine the self image this child will have if he gets at least that? A lot of little ones are just roaming around. Walking around. (On the other hand) a lot of kids that are growing up with parents that are spending time with them, oh, they're just walking proud. And what person getting a lot of love and attention at home, isn't going to walk with their head up in the air (feeling positive) . It goes right down, right back to the parents love.

- 2) Children need to develop high self-esteem.

Donna: Self-esteem and confidence. I

mean you may live in a poor environment and you may not have the best clothes and all that, but you still have self-esteem. You still have qualities that can make you whatever you want to be. You have to start out with goals... You can be whatever you want to be. It may take a little work and you may need more services, more outside help. But you can still do it. But I think it starts from self-esteem and confidence. I know we have a lot of people that grew up with nothing when they were little. They lived on you know, flour and water, and they're some of our lawyers, politicians or whatever... I think it was due to the love around that person and the bond. If you have enough love and stuff you can make it, it's there.

Donna: ... Some kids do (develop high self-esteem). Here again I think it comes back from a stable home life. Kids that have had that from the time that they were babies... they believe they can. They can do well and they do believe that. But if you had kids that didn't (have stability)..., thrown from one house to the other, from one school to the other... It's like when you go through a divorce. You feel like it's your fault. Something along that line. I mean it may not be your fault. It may be it wasn't your fault. But it's always; gee maybe I should have done this and I shouldh've done that... I think that (instability) would be very hard to grow up with. (Kids might think) maybe if I hadn't been bad lots, I would have had dinner today. You know that type of thing.

Children Need to Experience and be Active Participants

In addition, providing children with opportunities to experience and participate in a variety of different settings, was viewed to be beneficial. These ranged from

daily routines such as shopping, and accompanying parents when travelling, to attending cultural events and spending time with other community members. Learning by doing, and meaningful participation, were seen as important.

Donna: I think they need independence but they also need education to the outside world... I used to go on school trips and a lot of children have never left the reserve. I really think it's a scary thing for them. You have to educate them that there are other things outside this area... Things that we take for granted they had never seen before. Some have never left (neighboring community)... I think just educating them that there are other things outside this area... Maybe (the problem is) lack of transportation. Probably a lot of times the parents go to (neighboring community). Go get groceries or something and it's easier to leave your children at home. I think that if you (the parents) took them (the children) on your grocery trips, the children would know what grocery stores look like. Now this is the meats and that. I think even with things like that it would be helpful or a learning experience.

Donna: One cycle. You're born here, you're raised here. Your Mom and Dad did a certain thing and you do the same thing... It's just one cycle and they have a hard time going outside that cycle. They have a hard time adjusting. You only know one thing, so what are you going to do with that one thing?

Bob: I think around here...I like to come back to the extended family philosophy of the Native way. To them they feel that they (children) will

learn through inter-reacting with grandparents... They will learn certain things with inter-reacting with other siblings within the family... They will learn by inter-reacting with other children at certain events like a round dance or something like that... That's part of the cycle of their learning... The child continues to grow and they grow for socializing. They have their growth for developmental abilities within the child. All growth molds. These different things; inter-reacting with different people; inter-reacting with the environment around them.... Everything around us is important if it has a specific function in life and this is what the child learns from... All their activities is the entire community. It's not just one block party or whatever. It's the entire community and the child sees this...

Responsibility for Teaching and Guiding Children.

Responsibility for teaching and guiding children rests both with the community as well as the family. Participants saw the community as having influence in supporting and guiding families.

Steve: ... We have this great big building and we have residences. And I thought about it a lot. We just have to say it and start things to help these children (with special needs). They belong to all of use so we should all work together to help.

Rick wanted to see help being given for children. They need to feel they belong to a family, and part of belonging to a family is belonging to a culture. They need to understand and take pride in their roots. More culture needs to be taught to children who are very young. Their parents can't teach them because

they, the parents, no longer know their culture. There aren't many Elders left to do the teaching and he is afraid this might be lost. He knows though that in his family, his daughters, more so than his sons, are teaching the culture.

Donna: I think a lot of them (what children are presently learning) are survival skills. Educate them (children) in their own way, to their hunting... The little guys, I think it's important they learn that way, from the Elders and community.

Definition of the Term "Handicapped" or "Disabled"

Two distinct versions of this term emerged from the participants. One version saw handicapped as referring to those individuals who are not being nurtured or not receiving love. It was felt that these children are left to grow up by themselves and are handicapped because their basic needs have never been met. Being emotionally handicapped was seen as more disabling than having a physical handicap or learning problems.

The second version defined handicapped or disabled individuals as those who are not able to participate to the same degree, whether physically or mentally, as other community members, and are therefore more dependent and less fortunate.

Not Nurtured or Receiving Love

Liz: Handicapped, handicapped I guess... Not ever having received love unless you're a baby and fortunate enough to have received a lot a love. To grow up without having had somebody really totally care about you... Growing up by yourself is like being handicapped. Being alone. Not really wanting to be, but having no choice... And believe me a lot of the kids are really handicapped. I guess you could say... they've grown up generally raising themselves.

Not Able to Participate to the Same Degree

May was quiet for a while and then she said she feels sorry for them. She thinks it is hard enough to be a Native child today with all the problems around them. At the same time, she sympathizes with them. (May gave an example of her own situation). Getting around is very difficult for her and she finds it hard to be dependent on others. Her husband had to be hospitalized not too long ago. She goes to visit him in the hospital. Now she has to feed him. Before he used to cook for her since she had so much difficulty getting around. Before, they used to live in a small house beside the larger house her son lives in. She cannot live on her own. Her son and his wife now care for her. Many old people and children have no one to look after them. This is all part of the family falling apart.

Paula's definition of handicapped: people that can't help themselves in any way, who need assistance and are therefore dependent. She did not feel that there are many handicapped persons

in the community, except for some elderly people. She found that children with handicaps are difficult to identify because they are mostly in the homes and not visible to the rest of the community. Most kids with problems aren't that handicapped. Rather they are slow, but in many ways no different from other kids.

Community Acceptance

Participants who held either version felt that handicapped or disabled did not mean that the individual was any less of a person, and should therefore be treated the same as other community members.

Donna: Actually,...I think that the reserve people accept it (a person's handicap) and deal with it almost better than I'd say we do in (neighboring community), because they are so bonded together as children. They look after each other. They'll deal with the handicap. It's just another child who may have a problem... It's not something that they really dwell on. They don't see it as a problem. It's just that,... that's the way they are... We have some children here that have FAS, and multiply handicapped, severely. I have a girl (in her class) who is visually impaired and she's just a little girl. Maybe she can't see quite as well as the rest of them. But she's just part of them. They play with her. Sometimes I think that outside (of the Reserve) they generally tend to stay away or they stare at things like that. But here it's nothing, it's just part of what they are... I think adults are the same way... They're not scared to talk about the handicap here. Whereas in (neighbouring community) you may see that there is something wrong with the child, and then they talk about it at

coffee. But they never really talk about it in the open. That type of thing.

Steve: When somebody uses the word handicapped, (pause) they think of less fortunate than other children. (Others think that) if you are handicapped it's more or less that you're not able to do anything for yourself. Less fortunate than other children. This isn't always so (that handicapped people are unable to do for themselves). You can understand then that... telling you (a person with a handicap) that you're not able to do anything for yourself... Handicapped is not used right.

Personal Evaluation and Experience with Existing Services.

Participants brought forward some interesting insights and opinions of existing services for families and children with disabilities. These observations were made by individuals who are directly involved with services for children with disabilities, and from others whose family or community members were involved with these services.

Participants Questioned the Value of Centre-Based Services

Most participants questioned the benefit of centre-based services, meaning those outside the immediate community, which required significant travel.

Sue: ... two (assessment appointments).
One in Saskatoon and one in North

Battleford. In Saskatoon they did an assessment. In North Battleford he (her son) saw speech and language (pathologist)... No (appointments weren't helpful)(silence). They (the professionals) saw him for one hour and said he couldn't do things (silence). They (professionals) don't know what he's like. He didn't do anything. It was too different (the environment)... (Her son) Felt tired. I had my baby with me. I was happy to go home. I have more kids at home. They told me he is slow and can't speak (silence). So I went later to see speech in North Battleford (silence). She (speech pathologist) said he was autistic. (silence) I didn't go back. ECIP started coming out in July (silence). They (the professionals) don't know his problem so they just send you to see someone else. You don't know why.

The Health Nurse did tell me that when Sue was in Saskatoon for assessment with her child, they recommended that he stay for one week observation in the preschool. Sue said no. The Centre called the health nurse to get her to try and change Sue's mind. The health nurse felt that if Sue said no she probably meant it.

Jean found specialists' appointments very stressful. Arrangements for travel, time away from work for her and her husband. When their baby (one of twins) was in NICU (Neonatal Intensive Care Unit) they had to travel to Saskatoon all the time. They thought things would be different once their baby came home. They were then told to go to all these follow up appointments. The parents usually weren't sure why they were going to the appointments. They didn't think they were useful, but went anyway. They wanted to do everything for their baby, especially after one of the twins (the one who wasn't in NICU) died, unexpectedly. Jean was only able to keep

appointments because of family support and their willingness to care for her other children, while she and her husband travelled to these appointments. Her brother moved up north to stay with the family for six months to help out. At these (specialists) appointments her child was often over-stressed and not performing to her ability. Jean and her husband felt that their child was being inappropriately assessed. Some information and recommendations that were made were culturally and environmentally inappropriate. The professionals did not seem to be aware of this.

Jean referred to the lack of awareness by professionals of existing community services, and needs that parents have identified. She went on to say, "People in Saskatoon had no idea of what other support services they could have referred me to in my community. They only know about what they do at their place."

Paula identified five concerns about accessing services which require travelling outside the community. These were as follows;

- 1) Transportation difficulties and extensive travel time.
- 2) Coordination of childcare for those needing to be left at home.
- 3) The families' comfort level. Families often feel threatened, intimidated and uncomfortable. There is the issue of language barriers. All of these add a lot to family stress.
- 4) During these times the children are often not themselves. They usually act very different at home than in a clinic in a big town. The same goes for the parents. You never get to know their real personalities.
- 5) The professional doesn't know or doesn't bother to find out about the child's home environment or cultural background. Therefore the parents

can't relate to the recommendations made, and there is little consistency or follow-through.

Services Identified as Valuable; Community-Based and Home-Based

The most valuable services were those which came to the community and to the homes of individual families. These services included the home-based Early Intervention Program (from a neighbouring larger centre), and the home visit services from the Health Nurse (who is employed by the Band).

Paula felt that services could best be provided in the home. Early intervention or another similar type of program needs to be controlled by the community. She felt there would be a difference between services out of community or in community. Out of community services, from her experience, are very child focused. On the other hand, in community services, can't help but be child, family and community focused. She felt that families would be seen more regularly and probably be more willing to follow-through on any suggestions.

Jean felt that she and her husband were better able to respond to the specialists' suggestions once early intervention (home-based) started, primarily because of the support they received. Jean and her husband eventually opted for early intervention (home based) services, instead of specialized therapy services (centre-based therapies). They felt, however, that early intervention services were stopped too soon. Their child had made a lot of gains. As a result, their daughter perhaps was not

seen as a priority by the early intervention program, yet the family felt that they could have continued to benefit from the program. Jean saw early intervention useful both to herself and her child. Jean also stated that she wished she would have known about early intervention sooner. She could have used that help and support when the twins first came home.

Sue: I used to do everything for (her son) but ECIP (Early Childhood Intervention Program) told me I should help him learn to do things for himself. He got mad and didn't want to, but now he knows and can dress himself, gets his own snacks and drink. I guess it's easier now.

Doctors Occupy Different Status

There was a distinction made by participants between doctors' appointments and appointments of other professionals. Frequency and the need for doctors' appointments were questioned less and seen as more important. The impression received was that doctors maintain a fairly high status with community members.

Donna: ... I think if it (advice and guidance) comes from... the doctors, people listen. I mean that's what they're trained for....

Bob: ... They will allow a doctor to (give advice and guidance), because a doctor is a different person... He is a medical man that can be there to heal their child if their child should be sick.

Issues in Dealing with Professionals

Participants expressed a general difficulty in dealing with professionals. In retrospect, participants felt that they lacked the confidence to express concern, or question the recommendations made. Rather, participants said they, and others rely on the Health Nurse for support and guidance when questioning recommendations or requesting clarification. This was also noted in my observations when visiting the Health Nurse and spending time in her office. There were numerous times when individuals just came to her for advice on a recommendation, requested clarification or more information.

Paula saw a need to coordinate services. Maybe through the Health Nurse, or a committee that oversees the ECIP. The Health Nurse right now is used a lot by the community members as a second opinion. Rarely do individuals feel comfortable enough to question recommendations made by the professionals, yet they don't hesitate to express their feelings to the Health Nurse. They will sometimes tell her why they didn't want to keep an appointment, and then they just didn't show up.

For Jean some information and recommendations (regarding her child) were culturally and environmentally inappropriate. Professionals did not seem to be aware of this. Jean and her spouse did not want to say too much because they felt they still needed all the outside help they could get. Jean found the Health Nurse to be supportive

in listening to her concerns, and helped her sort out which appointments were important for her child.

Beneficial Elements of Services.

Services That Provide Support and Guidance to Families and the Child

Services which provide support and guidance to families and the child were identified as being most beneficial. All participants expressed a concern for the well being of the family, not just the child with the disability.

Paula felt that a service needs to be more than child focused. It needs to address the family's needs. A service for children also needs to hook up with NADAP (Native Alcohol and Drug Abuse Program), Social Development (existing community based services). She identified concern with NADAP. They are not doing everything that they could at the present time.

Jean also expressed concern for those (individuals) who don't have the self confidence to trust their instincts, and who have no constructive support. These families and their kids are really lost and usually the problem gets worse with time instead of better.

Steve: What should be done about it (meeting the needs of developmentally delayed children)? I really put aside the idea of taking children from their home, and the environment too. The families know. (It's not good for these children) if you take them away from the home, from brothers and sisters and their friends. That can't continue. We

have to get some program, help more near to those children and the parents. Then the parents are the winners too.

Elements of Most Beneficial Support

Participants identified the following elements as being most important for providing appropriate support; (1) home visits, (2) services to mobilize parents, (3) finding out about resources, (4) support at the community level, and (5) having children with disabilities actively participate in the community.

1) Support to the home via home visits.

Participants identified their own family networks as providing them with the most strength and saw home visits as reinforcing these natural supports. In addition, having someone come to the home also provides a break for the parent, and sometimes the only opportunity to share concerns. Bob, for example, felt quite strongly that parents and children are more at ease in their homes, and consequently they may start to see themselves as more directly involved in decision-making for their child. Becoming familiar with the home setting would allow for more appropriate recommendations to be made by the professionals.

Bob: ... That child has come out of her womb and she knows what's best for the

child... Any person who's going to come and tell her do this, or do this... they (the mothers) may retaliate, especially if the person does not know the home or has never visited there... But any individual, be it a teacher,... or just another person off the street, coming in and saying, "Hey I do it this way", without seeing what the home is like... that's telling somebody you got to do it this way and ... they (the mothers) are going to be putting up a wall... That's one thing that I have noticed about intervention that is centre-based (mothers resist recommendations made by professionals who never see the family's home, because these professionals lack of awareness of the home situation) ... Sometimes that's one crippling effect that they (professionals from outside) will have on various communities. Especially ones that have very strong cultural embedded in (their) values, like say on this reserve.

Jean identified family support as the greatest strength to coping with a child with challenging needs.

May spoke only briefly about helping children with handicaps. She did feel that help needs to be given at home... The home and the family need to be strengthened and helped if any child is to benefit. Taking children away she sees as making the problem even worse. She feels that if parents learn to love their children, they can find the strength to help them as well.

Paula felt that services could best be provided in the home. Getting into the home is very important primarily for making sure recommendations are appropriate and also because of the message it sends to the parents. By going to see them at home, you are saying that they are important enough for you to take the time to go and see them. If the parents start to feel more

important, then they will start to see that they do have a right to make decisions, and are responsible for the decisions that they make.

2) Services need to mobilize parents.

Participants saw a need for support services to mobilize parents to seek help, and build their own level of confidence in order to cope with their child's needs.

Val: Maybe if parents knew of programs, these kids would come out. I think we'll have many more of these kids (with special needs) because so many young people are taking drugs and drinking a lot. When they have kids that have problems, they don't know where to go or what to do...I think that is why so many (kids) are ignored, things aren't done for these little ones.

Jean summed up some of her feelings by saying,
"You're often wandering around in the dark, by yourself, relying mostly on your gut feelings and your family. My concern is for those who don't have the self confidence (to mobilize), to trust their instincts, and who have no constructive support. These families and their kids are really lost and usually the problem gets worse with time instead of better".

3) Coordination of services.

Participants felt that it was important for families to know what resources are available to them, how to access them, and the coordination of these resources.

Bob ...as a parent that's what I'm looking at because I'm running here and I'm running there and I'm running all over the place... It shouldn't be that way. The point is... governments should... meet the needs of these children and let's make sure that everybody is working together... instead of going around and around ... That person (the parent)... has to go to the different agencies to meet the needs of that child. (They have) other children that they are responsible for...I was just one of the unfortunate parents that were caught in that little scenario where... You commute over here to make sure Jay takes his physio twice a week. And you make sure that you go up to (assessment clinic in Saskatoon) so Jay gets this. And you make sure that he is over here in this daycare centre and we'll get him a program over here. And then you go... to ... coordinate with the (assessment clinic), and see if you can get this program all in place... Then we'll make sure that we can mainstream him into this school. And it was all these different agencies that were either working with or working against intervention... Somewhere along the line someone really doesn't understand what intervention was all about. And I think it's just certain agencies not communicating and talking to others... Maybe it's a fault of (Education). I don't know, but somewhere along the line somebody doesn't understand what the real intervention is all about.

Paula had concerns for those families who are involved with many agencies. Agencies in her opinion often work in isolation and leave it up to the families to piece things together. What she often sees happening is that families either don't have the skills or energies to do the piecing together, or they use the situation to play one part of the system off on the other. In these

cases it's usually the child who loses out in the long run.

4) Support at the community level.

Families need support from the community. For community support to exist, there must be an increased awareness in the community of the needs of individuals with disabilities and their families. Some participants felt that there was support from community leaders to address the needs of these children. However, other participants felt that the community must first address the larger social issues of neglect and alcohol abuse.

For Jean an area of concern was community awareness. She felt that if the community doesn't understand or is afraid of the children and their needs, it cannot act as a support.

Steve: If it got started on the reserve I would like to see those parents who have those children (special needs) have a workshop with other parents that don't have children in those situations... If we have parents with those children and other parents we should get more strength in the program, than just having the parents of those children (with developmental delay) sit to one side. This is the first time we really have information on these (developmentally delayed) children. Before that I wasn't involved with the school. Now I'm chairman of the school board and get it (information) directly from the principal. So when it's these children we're talking about, it's not only the child we should be looking at but the parents also. And other people. Tell other people about it, so that they

can understand and hear about these things. We're more or less trying to help, not just deal with it in the school. It seems mostly left up to the school.

Bob: I think right now on this reserve the ... The leaders on the reserve have acknowledged special needs children. They have acknowledged them and they know that they have a right and they must try to meet their needs ... They (Chief and Council) are prepared to bend over backwards to accommodate them by bringing in... like yourself, and other people to assist them... That's the key word to assist...

There was general agreement among participants that the community must address issues of abuse and neglect. Both Liz and Rick on numerous occasions expressed their frustrations with the lack of community involvement in situations of abuse and neglect, and subsequently little being done about it.

Liz: ... If the welfare people would look at the home situation, listen to people telling them about these families. Maybe if the welfare services here were to tell the Chief and Council this (the concerns that exist). Maybe they would buckle down and try and talk to these parents. Somebody's got to talk to these parents (who are neglecting and abusing their children). Nobody's ever (talked to them). I've never seen anybody go and talk to them. It's just really, okay it's your life so live it. That sort of thing. It shouldn't be like that because there's so many little ones involved. You know, I think the first step would have to be that the welfare services have to look closely at these

families instead of every two weeks giving the parents their cheque. You know, they should make home visits. I don't think they've ever done that. Really take a look at these kids. Even in the evening after work, on weekends. That's the best time. Go to these homes and talk to these people, if you're lucky to find them at home. But most always those kids are alone weekends. Then they (social services) will see for themselves. They don't have to wait for a death or something before they step in. Because that's almost what's going to happen. Then you're going to see all this phoney concern. I call it phoney concern because if they were really concerned they'd be there right now. You know. The same things for Chief and Council maybe.

Rick talked about the importance of community support. Healing groups to help those who are wanting to be helped. Rick feels that there are too many people who don't know how to help themselves because they don't believe in anything. Help must be given in the community. Children should not be taken out or away. In the past that has only made it harder. He felt that the community needs to seriously look at its resources because many of the old people are getting very old and can't care for so many children any more. The young people have often thought that the old people will always be there to look after their children and therefore haven't learned how to do it themselves. He was very concerned about what will happen when the old people are gone.

Jean felt that lack of community support results in isolation of the child and caregiver (generally the mother), and does not contribute to their feelings of self worth.

Jean said "You don't know the importance of a service until you have to use it yourself". She stated that unless you have a child with a special need you have no idea of what it takes to keep going day after day. And these are things on top of your regular daily problems.

- 5) Having children with special needs actively participate in the Community.

There seemed to be agreement among all participants that children should be accepted into the community as part of the community. Examples were given as to how this is already happening. Children with disabilities have been integrated into the Reserve School. Some concern was expressed regarding the visibility of children with disabilities in the community prior to school age.

Rick said with respect to special needs children, what is good for all children is good for them too. They are part of the community and should be taken care of by the community. "I've seen retarded kids learn".

Rick alluded to the fact that he would now be considered disabled, but that doesn't make him any less of a person than if he could hunt and do more things. He applied this rationale to handicapped children. He wanted to emphasize that we need to find out what are the things they can do, and help them feel good about that. "Everyone of God's children can do something".

Steve:...I always try to think positive about it. I always say to myself that they (children with special needs) are going to be able to overcome the situation. I don't treat them different, or more or less putting them aside. If you believe that you're going to overcome that situation, at least then you're thinking, you're hoping that they are going to. And those kind of thoughts need to be with the children.

Bob: To give you a good example before I took this job they explained to me about the three children... The community literally hid them. They (the parents) didn't want them going to a school or anything like that...Protected them, kept them away. And by the time that the school board was aware of this, and caught on to what was happening. You know the whole community got involved because they were concerned... Let's get these children and help them... Because the director has a very good sound background with special education, that started opening more doors. And as soon as more doors were opened we finally got these three into school. The only problem they (the teachers) had in implementing that program, bringing the child into the school, is that they (school administrators) placed that child in my own personal opinion in the wrong atmosphere. Like a child that is eleven years old you don't put into kindergarten. And you know that to any person is humiliating. And if you start to humiliate a child you take away their esteem, and that's just one area that we're trying to restructure and correct right now. We are attempting to put those individuals in the proper placement for chronological age, physical stature and all of that... It's tough but we're getting there... The point is ... if I could take you in there (the classroom) and show you, you could not identify that one child.

Planning a Service or Program

There were a variety of ideas generated by the participants. These ideas have been synthesized into five main categories; (1) when should services be provided, (2) location of the service, (3) intervention model, (4) should the service provider be from the community or come from outside, and (5) community involvement and support is seen as essential.

When Should Services be Provided?

The general feeling was that services should be provided as soon as possible regardless of the child's age. However, families should be the ones requesting the help.

Paula felt that home-based services should start as soon as possible. She felt that the parents consent and desire to access the program was an important factor to be considered prior to a referral. Frequency of visits should be flexible. Perhaps once every two weeks would be good.

Donna: ... I think it should start from when you see a problem... The problem (developmental delay) identifies whether they start or not... The parents need to understand why there is a problem and why it is good to get help.

Where Should Services be Provided?

It was generally felt by participants that services going into the home would be the best option, especially for very young children.

Bob:... Visitations, go into the home... Assist the parents to become, and the grandparents to become, more involved in how to structure a simple little lead up program (intervention) for the child... How you can integrate certain things in daily experiences, into the program ...

Sue: For babies and small kids help in the home, not too much though. Maybe like Lee (present ECIP staff), once every two weeks.

Liz: Well the only real place I can see for it...to start is right in the home with themselves (parents) to start. It's got to be (in the home)... Here the mother might have one too many kids to look after (therefore it is difficult for her to get away). But a lot of these kids are school age and they are in school (during the day the home wouldn't be too busy). You could start looking at the younger ones (those not yet in school) because most often, there is a younger one at home (who has needs).

Donna however, did express some concerns regarding the comfort level of parents, with professionals visiting them at home.

Donna...They are very private people... They don't like... Unless you are invited into their home, you are not very welcome there...I think you have to be more in a professional setting as in

a daycare centre or something to give the help. They don't like you going, coming into their home. You're invading their privacy, and unless you have that rapport between the parents and the professional you wouldn't be getting anywhere... We have tried with the home visits for our report cards and it's just not, it just doesn't work. They just don't like you in their home... That's their space there, and you're invading their space... They're not going to work well with you if they don't want you in their homes. They're not going to work out. But if they have a choice... Say okay I can take my child here. Or between you and the parents decide we can work at home. Then you know... It's got to be definitely, you both have to agree on it.

As children reach the preschool years, participants identified the need for children to spend time with other children in supervised group settings. Daycare was seen as a stimulating environment to support children's development. This option could also provide respite, or break times for caregivers and an opportunity for them to socialize and get out of the home.

Steve: I believe that (daycare) would be a very good idea. Having these children to be with other children in their age group, that would help them to be better prepared for when they have to go to school... I believe that that's a possible thing (using daycare as respite). That it's a very difficult thing they (the caregivers) are doing, looking after them (special needs child) day after day. They get frustrated. The problem is you have to have money for that.

Sue: (silence for a fair stretch). Ya, he runs inside a lot and climbs. It'd be good if he had a nursery school (silence)... Ya (silence) (response to whether nursery school would give her some respite). Maybe he'll go to the class at the school... Ya (response to whether a nursery class now exists in the community), they have to be 4. It's Liz's class. It's two days a week all day (silence). I think he'd just go mornings.

Rick stated that he would like to see a day program set up where all the children go together. Where they could learn with guidance. The parents should have to come and learn also.

A daycare setting could also facilitate more opportunities for parent education and parent to parent support, where parents could learn as a group. Community members could share their knowledge and insights regarding child rearing practices and cultural values.

Paula saw that the daycare setting would also promote an option for parent education. Presently the nursery and kindergarten teachers are trying this option. She felt that it is easier for parents to accept (suggestions) if the focus is on the kids instead of themselves.

Rick felt that it was important to help children learn to feel they belong to a family and part of belonging to a family is belonging to a culture. They need to understand and take pride in their roots. More culture needs to be taught to children who are very young... A daycare setting would be a place where

parents can meet too, and some of these teachings could happen there...
Donna:...I wouldn't want somebody coming into my home and saying, now you're doing a lousy job. Nobody, nobody wants that. But I think if you did it (parent education) as a, maybe a support group... You'd have to start out small and get people who are willing to get, to start out, are open to the idea that maybe I do need this... Maybe this would help... Do it... something like that. Then you'd have to work the children into it... Putting ownership back on the parents to make a decision... Because then they are part of it. They feel like they are part of the it (decision-making about their child). They're not feeling like you know degraded, or what's the word I want to use?

Intervention Model

The general feeling among participants was that the needs of the individual child and family would govern the intervention model used. A recommendation made by some participants was to provide guidance to parents by modeling as opposed to instructing or teaching.

Bob: ... You don't, you can't teach you know (parents respond better to learning by modeling than to instruction). Once you teach them that means you are, you're telling them this is the way it should be... When we (professional) start telling another person how to child rear you're asking for trouble. But to show them something, and let them do it (modeling), is the thing. Fern, (early interventionist from another community), she was on top of it... because she was a mother and she could understand where they (the parents) were

coming from... That's the one thing about native people... Fern used some very ..., unorthodox procedures, approaches. But they paid off for her... I liked the way that she presented something to them. She would just say, "this is, let your child play with this." (She would) just give it to them and sit down and have tea and let the child investigate. (She) didn't even show them exactly what was going on, but they (the parents) learned from that. Right away (they) learned something and wanted to know more about it...

Understanding the culture of the community is imperative if intervention is to be meaningful and accepted by the members of this community. Some participants spoke of the need to revisit and reinforce cultural and traditional ways of parenting.

Bob:...there is that, that great hold for the Cree language and they really want the little ones to understand and speak it... Be aware of certain Cree words... It's good and I think the young ones can understand that and they can really relate to that. I noticed that many times now... I've been to two of three homes already where I've noticed a little three or four year old child quickly, automatically be magnetized to the grandparents because of the Cree language and they understand everything.

Bob: To give you a good example... In the Indian way they don't believe in disciplining the child by spanking, hitting them. You never ever hit a child. That's the old way. That's the way they believe it to be. Now they also teach the child that you shouldn't hit another child because they (children) try to... This is what will

happen, this child will cry... and you hurt... It's just something that's passed down from age to age... You're not allowed to hit a child... Pat on the backside or something like that you just don't do. They (Elders) feel by talking with the child and showing the child what would happen if you should hit someone, it hurts. I think about the time when a very dear lady to my heart called Kookum. She took care of my children. When they did something wrong she would just lightly give a little pinch so that they could realize that it hurts. That was one learning technique, or procedure, that she used to do... So in their own way they would teach, in a different way than (non-native) do.

Rick described how in the Indian way work meant strength and survival not monetary gains. Hunting was survival, all sorts of work focused around hunting. Also many of the ways of nature were taught through hunting. It was hands on learning about seasons, animals, cycles, weather systems, changes in environment. Today Indian children are taught by books and not by doing... Women's work revolved around hunting as well. She would smoke the meat, tan the hides, make clothing etc. Today his wife who is 79 still does all these chores including chopping wood for the house and smoke house. Possessions were those that were made not bought. Today's concept of money and land is hard for Natives of the old way to understand. Land belongs to everyone and is to be shared and respected, taken care of so that it will continue to provide... Indians did not understand what they were doing when they gave up land for trinkets or for exchange. They had no concept of the white notion of selling or giving up land. How can an individual give up something that already belongs to everyone. How can you prevent people from using land, rivers that belong to everyone. (He seemed very

quiet, reflective, so I waited until he spoke).

Who Could Best Provide Service.

In general, participants did not seem to express a definite preference as to whether the service provider should be from the community or come from outside. Personality and qualifications were seen to be more important than residence status.

Sue: Doesn't matter (if service provider comes from reserve or from outside community)... No. (didn't feel a person from the reserve would necessarily better understand her needs).

Jean felt that the person who provides the service needs to be qualified and have the training, but also needs to understand what it's like for these families, and what is needed to help them cope. She felt that it wasn't always easy to find these kinds of professionals.

Paula discussed who could best provide services to families. Whether it should be someone from the community or from outside the community. At present, she felt, it would have to be someone from outside as there isn't anyone in the community who would have the right training. She didn't feel that it really mattered all that much if the person was from the community or not. From the parents' perspective however, they might prefer someone from the community. But then again maybe not, since then some privacy issues could come up.

However, some of the comments included concerns

about privacy and confidentiality if the person was from the community, and how seriously they would be taken by some of the families.

Paula went on to explain how they (the community) used to have interagency meetings. There was a lack of confidentiality by some staff(during these meetings). This is a big problem on the reserve, primarily because of one worker. It is a small community and word travels fast. The Band is aware of the potential problem.

Liz: Maybe there is somebody from out of the reserve. 'Cause if it were somebody from in the reserve they (the parents) wouldn't take it seriously. Don't ask me why, I just know... When we try to talk to these parents they call us saints or whatever (she feels that she and her husband are not taken seriously)... It wasn't very nice. ... So you give up on them. And if there is somebody else that's gonna try and go talk to them, 98% chance they're going to get the same treatment we did. You see these women. I don't know what's wrong with them. They think... Hey I'm their mom I know what's best for my kid. But if a mom knows what's best for her kid, I don't think she'd be leaving them by themselves. I think she'd try and spend quality time with them and she'd really try and help her two FAS children. You know, those (parents) are the ones that get so defensive. Is someone else going to throw them out and then they'd have to live somewhere else with somebody they didn't know? They don't have the strength... I think they would listen (to someone from outside the community). Like, when there used to be these women working with that family (early intervention from neighboring community). I'm trying to talk about one family, just as an example for this one.

They actually used to try and do something with these children, the mom and the grandma and the uncle.

On the other hand Donna felt that a community member might better understand the culture and environment and therefore be trusted more by families.

Donna: I think you would have to start from within the reserve (the individual should be from the reserve). They have a hard time trusting. Like it's taken... It took me awhile for the kids to learn that they can trust me... I'm Metis but it still took them awhile for them to trust me, and to know that it's all right to be my friend. But they still looked at me as the white women from outside... But now they know me. They know what I do. We've gone on school trips. They've gotten to know me a little bit outside of school and they can see me downtown or that. I would think that you would have to start from within the reserve and then get your people here from outside the reserve and... You have to (the person making recommendations needs to have status in the community), sure you would have to. Because I would feel that they would feel that the white people are moving in on their territory... For instance our guidance counsellor who lives here is from here. She knows everybody... She can confront and will say for example, let's say they're not feeding their children. She can go to their home and say, listen I have to report you if you don't feed your children. Like you're not clothing your children or you're... She can do that. But if I went there with the same job as the counsellor, and said, you know... It would not be accepted the same way. They'd be saying, by a white women stepping in, who is she to tell me. See the difference. She's

(the guidance counsellor) been here, she's... Sure (she has status) you know she's grown up here and they can respect her telling them.

Community Involvement and Ownership.

Many participants equated community involvement and support with increased community awareness and acceptance of responsibility for problems. Increased community awareness and ownership of services for children with disabilities was seen to be part of the community's healing process.

Rick wanted to see the establishment of more community support, healing groups to help those who are wanting to be helped. There are too many people who don't know how to help themselves because they don't believe in anything... Help must be given in the community. Children should not be taken out or away. In the past that has only made it harder. He felt that the community needs to seriously look at its resources because many of the old people are getting very old and can't care for so many children any more. The young people have often thought that the old people will always be there to look after their children and therefore haven't learned how to do it themselves. He was very concerned about what will happen when the old people are gone. .. With respect to special needs children, what is good for all children is good for them too. They are part of the community and should be taken care of by the community. "I've seen retarded kids learn".

Paula felt that an early intervention or

another similar type of program needs to be controlled by the community. She felt there would be a difference between services from outside the community and those developed by the community. Services from outside the community from her experience are very child focused. If the community developed its' own service it couldn't help but be child, family and community needs focused. She felt that families would be seen more regularly and probably be more willing to follow through on the suggestions... Some families want help ,some don't. You don't know who wants help until you get in there... Once a program gets started and people start to hear more about it, there will be more kids that start to show up.

Participants felt that all services in the community, including possibly an intervention program, must be coordinated, and must support one another. The services which were mentioned included the Health Nurse, Health Clinic, Social Development Workers, Native Alcohol and Drug Addiction Program (NADAP), and school personnel.

Jean felt that the program should operate in conjunction with the health clinic and health committee since it is their responsibility to identify problems and areas of need.

Steve: This (an early intervention program) would have to be, to be overseen, to make sure people don't take advantage of the program. There would have to be some way of accounting...Maybe through the health committee and working together with the social development workers and other

groups.

Paula identified a need to coordinate services. Maybe through the health nurse, or a committee that would oversee an intervention program. The health nurse right now is used a lot by the community members as a second opinion...She suggested a possible committee representation which would perhaps include; 1) parents of kids in the program. (A lot of times they aren't the ones who feel comfortable talking in public); 2) Health Committee representatives, 3) Band Council representatives, 4) Other interested people. NADAP representatives and Social Development representatives could perhaps also help, to coordinate services. But too many isn't good either.

Elders were identified as important community resources who could be used more than they are by the community, to give guidance and support to families.

Liz: ... there's lots they (children) can learn from the Elders. Especially when they (the Elders) come here to the school and talk to them. Which is only once every so often. They come and speak in Cree and a lot of these kids they don't know how to speak Cree let alone understand them. It makes it quite difficult if you can't understand somebody and what they're trying to say to you, you know. What sense is it going to make? Probably just sit there. Probably it would be just like me trying to listen to a Chinese person or me talking in Cree to him and neither one of us understanding each others language. It's almost the same thing. We started Cree with our little kindergarten kids. Try and get them to understand, give them some instructions in Cree and what not. That's only the

beginning. Maybe if they knew Cree they would understand what these Elders are saying to them. A lot of our Elders do not know how to speak English. Maybe the odd word but not enough to tell a whole story. And a lot of these stories the Elders (tell) would... give these kids a lot of meaning.

Bob: ... those three families,... they interact a lot with the Elders and they receive a lot of guidance. They (the identified families) do in their own way participate in a lot of cultural ways,... They'll get involved with sundance, or round dance performance to more or less breed some of the old way, some of the traditional way. They have their children involved that way too... It's something they didn't see before and are starting to see right now... That's where you can depend on the Elders because they always will give you good directions. I'm happy to see the parents take that way...

Bob: ...The (Elder)..., he makes it very, very clear that he likes to have his own grandchildren around all the time... Just the way that he reacts with them. He talks to them about the meaning of this and the meaning of that and tells them about different things related to nature... About the flight of a bird and what should happen with these things... He shows them his pipe that he carries and the sweet grass... He'll explain this is what's happening. If you've noticed the sacred circles that are out there (points to the hallway) with the skeleton, that's the sundance. (Rick, an Elder) is very involved... He's in charge of all of that so he takes his grandchildren right through it. The same with his wife (she is an Elder as well and teaches the young children). It's very, mysterious because he likes to just tell them so much at a time, keeps them always wanting to know more and more.

CHAPTER FIVE

DISCUSSION

POSITIVE INDIAN PARENTING

As adults they will face a world in which they will have to always work to prevent the loss of the culture, land and sovereignty. They must have strong hearts and good skills if they are able to be the new warriors whose weapons are the pen, the law book, and the spoken and written word. Not all will be warriors. Some will be gatherers, not of roots and berries, but of information about health, economic development, and education. Some will be story tellers, helpers, healers, and preservers of the traditions. To be these things our children need the help of their parents, and just as long ago they need strength, good judgement, social skills, self control and something to believe in.

(Northwest Indian Child Welfare Institute,
p.285)

Interviews with the participants revealed their feelings, perceptions, and experiences of how the community is responding to children, in general, and children with handicaps in particular. Concern for the well-being of all children and that children should be viewed as the community's greatest resource, was underlying most of the participants' comments.

In traditional Native culture children are very highly valued. Though the traditional spiritual beliefs that support parents to nurture their children may

differ between tribes, they serve to protect children
(Connors, 1988).

Many tribes view children as gifts from the creator that would be taken back if not treated well, others believe that children's spirits are loosely connected to their bodies and that they should be treated kindly and gently so the spirits will stay and still others view children as recent arrivals from the spirit world and as such possess special wisdom that should be attended to. Amongst my people it is believed that children should not be too harshly punished lest they die of shame.

(Connors, 1988,
p.5)

In general, participants were not concerned whether children had a handicap or not, but rather looked at children's needs from a broader focus. Liz best described this when she said "handicapped.. not ever having received love... to grow up without having had somebody really totally care about you..."

Associated with the well-being of all children was a shared genuine concern about parenting, including the effects on parenting of poverty, abuse and neglect. Participants shared some insights into why problems associated with parenting or its lack has evolved. Factors identified as influencing an individual's ability to parent include: a person's identity, historical events and previous experiences, and social problems.

These factors and their influence on parenting, are also found in the research literature. Surveys of social needs as identified by adults in reserve communities in Northwestern Ontario have "parenting skills" at the top of the list (Ross, 1992). Ross concludes that parents are aware that their children are increasingly at risk but feel ill prepared to find the most appropriate way to respond to their needs. For the parents there is a mismatch between the abstract concept of family and the reality of their own situations (Ross, 1992).

Personal Identity

The question of an individual's identity is complicated and has many features. Finding one's identity requires learning about one's culture and heritage. For aboriginal people, an additional task is coming to terms with what it means to be "Indian". Many Indian people, however, have been raised with varying influences of two worlds.

Individuals in the study community, for example, differ from each other concerning their experiences with the non-Native society. There are individuals who uphold the traditional values, those who assume values of the non-Native culture and those in-between who try to

reconcile the old ways with those of the dominant culture. The latter, those who seem to incorporate and blend varying elements of the two cultures are often referred to as "acculturated" (Berry, 1990).

Participants interviewed for this study represent acculturation and its possible variations. Rick and May practice and are guided by the beliefs of the old ways. Bob and Donna seem to lean towards the other end of the continuum, where values of the dominant culture have significant importance. Thus, what it means to be Native differs from person to person, depending on where they see themselves along this acculturation continuum. As well, the underlying cultural roots help to shape and influence parenting practices.

Parents struggling with their cultural roots, who attempt to raise their children with parenting practices that are not consistent with their cultural heritage, are not effective. (Connor, 1988). Cross (1986) writes that parents who are confused about their identity, cannot give their children a firm sense of identity.

Parental needs and those of their children are to a great extent not separable. For parents to learn about their child's needs they must first learn how to meet their own needs (Dunst et al., 1988; Connors, 1988; Cross, 1986, 1989). The ability to nurture, the basic

element of parenting as Liz defines it, is dependent on the individual's past experiences of being nurtured. Thus, for parents to learn to nurture they must first experience nurturance (Cross, 1986).

As parents begin to look at what their children face, they can begin to get a better idea of what kind of parent they want to be. To have strong children parents must find their own strength.

(Northwest Indian Child Welfare Institute, 1990)

Historical Events and Experiences

Historically, both the extended family and tribal customs supported parental responsibilities and communicated expectations of how children should be raised (Connors, 1988; Cross, 1986; Ross, 1992). Many of the teachings were done through oral tradition, myths, stories and teachings of elders, and all closely linked with spiritual beliefs. As a result of history, there has been a loss of the old ways and expectations are fragmented and unclear (Northwest Indian Child Welfare Institute, 1990). Parents now are often left to parent without direction and support and they face difficult challenges.

May expressed her concerns regarding the long term effects of residential schooling. Though these were discussed by some participants, they are not well

documented in the research literature, and have only recently been brought to light. Residential schooling was a direct attempt to assimilate or indoctrinate native children into the dominant culture (Haig-Brown, 1989; Ross, 1992). While this was not the manifest intent, removing children from their families and providing them with inadequate substitute environments during critical developmental periods has had significant detrimental effects on both the individual's identity, how they view themselves as members of their culture, and on their opportunities to develop good parenting skills.

As these people are the first to acknowledge, they came out of those schools with hardly any knowledge of family life. They had no role models for parenting except their teachers, and their experience during childhood was not of a laissez-faire environment but of rigid discipline, often coupled with corporal punishment. They did not experience any sort of reciprocal give-and-take between adults and children, any sort of day-to-day building of family dynamics. The people in this group are especially at a loss when it comes to raising their children, because they have no known family model to follow. They observe traditional parents letting children make almost all of their own choices without comment, and they contrast that with the regimented, pseudo-military experience of their boarding schools... Lacking a clear, family precedent in their own experience, these parents switch back and forth between the two extremes, confusing both their children and themselves. The result is a mixture of inconsistency and uncertainty, an

unfortunate combination in any context and especially so in the context of child-rearing.

(Ross, 1992, p.123)

Haig-Brown (1989), sees residential schooling as also contributing to the rise in alcoholism in Indian communities. Parents heartbroken at the loss of their children, struggling with continuing oppression, sought out alcohol as an escape. A participant in the Haig-Brown study (1989) on the effects of residential schooling concludes:

...two forces related to school contributed to her mother's alcoholism. Her mother felt unneeded, and in all likelihood felt that the children blamed her for sending them to school. She would have, on the one hand, the children pleading to stay home, and on the other hand, the government and church insisting that she send them to school. A desire to escape from these inescapable pressures is understandable.
(Haig-Brown, 1989, p.112)

Another historical factor considered by study participants was the childhood abuse suffered by many of the aboriginal parents. These individuals are survivors who must also find a different model of parenting. As Ross (1992) writes, their greatest challenge is to overcome the hurt, anger, and unfulfilled needs of their early experiences. Observations and concerns brought forward by Liz are examples of how some parents,

described in this study are focused on keeping their hurt numbed or denied, and of being afraid to learn new ways. Individuals with a history of abuse have learned destructive patterns which cause them to lack trust and to deny needs (Positive Indian Parenting, 1990).

Lockart (1981) brings forward the notion of historic distrust. Skills that are ordinarily used in establishing trust, warmth, empathy, authenticity, honesty and consistency, have been misused, misrepresented, or were completely lacking in past encounters between Native people and the dominant culture (Lockart, 1981). She gives examples of how past experiences with the dominant culture, such as wars, treaties, and some missionaries have fostered a foundation of distrust among Native people. Behaviours which have emerged subsequently, because of this distrust, negate the traditions of giving, sharing and respect. Consequently, these have a negative influence on interpersonal relationships, including parent child interactions (Lockart, 1981).

Though this was not a factor raised by participants in this study, it is worth noting. Perhaps it was not raised by study participants because of the nature of the study. The Health Committee and Chief and Council supported the study because the research focus was on

collecting community members' insights and thoughts, rather than an outsider prescribing a solution for the community. Participants seemed to speak freely and candidly about the issues which they raised.

Social Problems

Social problems such as poverty, unemployment, and alcoholism, all alluded to by participants, make parenting much more difficult. The day-to-day struggle which parents face to make ends meet will take precedence over children's needs. Though frustrated, Liz was very concerned about what she saw within her immediate neighbourhood, and about how to best help members of her community who were truly struggling.

Alcohol and its effects on parenting and the family was a concern voiced by all participants. For Liz, the alcoholic parent was preoccupied with his or her own needs, and was unable to meet the needs of children. Her fear was that these children are learning to hide their needs, suppress their feelings and not to trust. People who have learned as children not to need, not to feel, and not to trust, are not able to get their own needs met satisfactorily when they become parents and are not likely to be aware of the needs of their children

(Northwest Indian Child Welfare Institute, 1990). Paula and Donna commented on this cycle of unmet needs which they see in the community. Alcohol, poverty and unemployment have been passed on from one generation to the next. Any one of these three existential situations can have a powerful and negative effect on how a person feels about himself. Self worth, in turn, will affect what kind of parent that person will become.

The social problems existing in Reserve communities have resulted from outsiders radically altering the social organization of Indian people over a very short period of time (Ross, 1992). The implementation of the Indian Act, which requires each band to elect a Chief and council to act as its official representative in dealing with the Government, was a major organizational change for Native communities (Ross, 1992). Political and bureaucratic skills became more essential than dealing wisely and productively with the natural world, which was more the ways of the Elders. It is now uncertain which group will provide guidance to the community, the traditional elder whose philosophy may have little relevance to the bureaucratic necessities of the day, or the individual with the greatest aptitude for dealing successfully with the dominant culture. Ross sees that the traditional value structures, general

proficiency and wisdom, which fostered self-esteem and gave a person a place in the group, have mostly vanished in many communities. In its place is what he terms a "social free-for-all". Contrasting views fight for recognition as communities reevaluate the resources now needed for social cohesion (Ross, 1992).

CHILD CARE AND CHILD REARING

Child Care

Traditionally, the extended family provided an environment in which children were cared for by a network of adults, including aunts, grandmothers and tribal elders (Cross, 1986; 1989; Connors, 1988; Ross, 1992). Child rearing responsibilities focused on nurturing the whole child, physically, spiritually and emotionally (Cross, 1989) and were divided among many members of the community, so that no single individual was overburdened. Community opinion directed parents' behaviour and parents who did not meet community expectations were chastised and ridiculed into compliance (Cross, 1986, Ross, 1992).

Today, most Indian families are different from what they were twenty or thirty years ago. As well, many of

the natural support systems which existed then no longer exist today. Extended families often made up the communities. Today the family network has been weakened by both internal and external factors and is no longer providing this natural means of protecting children and support for families.

Study participants alluded to another community in this study site, the community of children. Many participants spoke of the strong bond between the children, how older children care for younger ones, and how children generally look out for one another. Daycare, an option brought forward by participants, could perhaps reinforce the bond between the children and at the same time re-introduce the concept of community and the network of the extended family in child care. It could also provide an opportunity for increased parental participation in child care.

Bob spoke of how modelling is an effective way to help parents develop more parenting skills. In many Indian cultures, learning traditionally relied on observation, participation, and story telling (Connors, 1988; Northwest Indian Child Welfare Institute, 1990). A Day Care setting could include these elements into its' program and also provide an appropriate cultural context and the integration of the support and wisdom of the

Elders of the community.

Child Rearing

Ethics and rules of behaviour of a culture govern child rearing practices (Brant, 1990). Members of the non-Indian culture often misinterpret observed Indian parenting behaviours. It is important for all of us to recognize that there are variations in customs, beliefs, ideals and aspirations of Indian and non-Indian societies, as well as psychosocial differences (Brant, 1990; Ross, 1992). Connors (1988) and Brant (1990) discuss four principles which govern traditional parenting practices and promote harmony within Indian cultures. These are (1) the ethic of non-interference, (2) readiness and respect, (3) emotional restraint and (4) time. Bob referred to these frequently in one form or another when he discussed traditional parenting skills he had observed in the community.

Ethic of Non-interference

The practice of non-interference is central to Indian parenting practices. Indian parents do not respond to "interfering" demands from their infants. Consequently, Indian children do not develop aggressive

attention-seeking behaviours such as aggressive verbal and oral skills which are reinforced by other cultures. The emphasis in interactions is mostly on observational and modelling skills instead of verbal skills and detailed direction by the adult. This parenting practice has often been misinterpreted by non-Indian persons as neglect.

Readiness and Respect

In traditional Indian culture the parent is required to respect the child's natural patterns of growth which are considered to be in harmony with the natural world. Therefore, the child will do things when they are ready and the time is right. This approach is seen as producing a more adaptive relationship between the parent and the child (especially significant for the child with a handicap), and may result in a healthier overall development.

Discipline and respect are taught through means which are intended to help the child develop self-control over his or her behaviours rather than by setting external controls. Teasing and shunning are seen as ways to draw a child's attention to their misbehaviour.

Verbal praise is very limited in Indian cultures.

The purpose of praise is to encourage excellence and humility and rarely takes the form of implying or reinforcing competition. Being successful is seen to be its own reward and should not be dependent on external attention.

Emotional Restraint

Emotional restraint is seen as an extension of non-interference and is intended to promote self-control and discourage the expression of strong or violent feelings. At the same time emotions of joyfulness and enthusiasm are also suppressed. Though the initial intention of the practice of emotional restraint was to support a group living situation and promote maximum harmony, it has also left Indian people somewhat vulnerable. Repressed hostility often comes to the forefront under the influence of alcohol and may be inappropriately exercised on a spouse, child or other acquaintance.

Time

The Indian concept of time has generally been misinterpreted by non-Indian people, creating problems between the two cultures. Indian children are taught to become fully involved in a task and to complete it to

the best of their ability. This requires disregarding artificial time constraints. Signs from the natural environment determine the right time for activities to happen. A good example of a time conflict which occurs between Indian and non-Indian cultures is the timing of the school calendar. The school calendar is in direct conflict with the natural calendar of the trapline, which many Indian families still try to follow. Families are forced to separate for long periods of time if they wish both to maintain a trapline, and to have their children receive regular education.

Ross (1992) concludes that these behaviours, which have in the past served to support family centered groups are contrary to behaviours required for successful encounters with strangers. Parents are now faced with the responsibility of developing new rules to govern children's behaviour. The ethic of non-interference for example, prohibits the development of rules in the form of advanced guidance. Combining the notion of advance guidance with enforcing compliance, both very much a part of the non-Indian culture's child rearing practices, cannot occur if the above-mentioned principles are adhered to.

SUPPORTS

Community Participation

Empowerment is an intentional, ongoing process centered in the local community, involving mutual respect, critical reflection, caring, and group participation, through which people lacking an equal share of valued resources gain greater access to and control over these resources.

(Cornell Empowerment Group; cited in Pence et al., 1992)

All participants stressed the need for support, involvement and acceptance on the part of the community. Participants saw that the stressful familial and extra-familial environment in which many families in this community live pose concern for the well-being of both the children and their parents and not just for families of children with handicaps. Hobbs et al. (1984) conclude that supportive communities are central to promoting human development and strengthening family functions.

A community-based approach provides multifaceted support, and is structured to address a variety of family needs. This approach directs our attention to promoting development rather than treating dysfunction (Halpern, 1990). Study participants indicated a desire to have a community program which could address:

- (1) the personal developmental needs of parents and their parental roles;
- (2) the cultural principles of child-rearing, involving parents in determining their level of participation in a program; and
- (3) the use of community members, such as Elders, as resources.

Other considerations brought forward by some participants included:

- (1) improvement in collaboration among existing community services (NADAP, Social Development, Health Nurse & Health Committee) and;
- (2) using existing physical resources (unused former education facility) to house such a program.

Resource Personnel

Participants shared their insights and opinions on whether resource personnel should be from the community or come from outside. In choosing an appropriate person the study participants recognized the need to balance knowledge and understanding of the community with expertise and familiarity with confidentiality.

Halpern (1990) reviews the advantages of a community hiring its own members to act as "culture brokers" to the larger society. By doing this the community takes ownership of the problem and its solution. This results in a reciprocal interaction between the community and families. Family preferences and needs are shared together with other items on the community's agenda.

Individuals from a community, hired and trained to provide services, are often referred to in the research literature as "layworkers" (Halpern, 1990). Musick and Stott (1990) and Halpern (1990) identified three characteristic strengths of layworkers. The first of these is acceptability both for initial entry into families lives and as a continuing presence in the community. Second is a greater opportunity for flexibility and responsiveness to meeting families needs. Third is intimate knowledge of the community's beliefs, life experience and living conditions.

Limitations of layworkers include; a tendency to be selective in what they perceive to be the family's needs, and the issues they feel comfortable dealing with; a tendency to take on too much responsibility for the well-being of the families; and at times the inability to set clear boundaries between themselves and

families (Halpern, 1990; Musick and Stott, 1990). As well, a concern raised by Donna and Liz was that if layworkers are members of the same informal networks as the families they are serving, a family may be reluctant to share personal and sensitive problems.

Because professionals seldom have the personal experience or shared history of the community, they rely more on the application of formally organized bodies of knowledge; they tend to operate in more goal-oriented ways; and often use the "authority" inherent in their specialized expertise to govern decision-making for families (Halpern, 1990). Professionals have generally had longer periods of time to develop skills and build a repertoire of resources and expertise, which are difficult to acquire over a short period of time.

It seems that the strength of one group is almost the weakness of the other. Layworkers have flexibility, availability and affiliation with families and the community. Professionals may have some of these strengths as well. They have to contend, however, with large caseloads; they are very expensive; and it is often difficult to get professionals to devote sufficient time to the community to provide the necessary level of ongoing support needed in many communities. When choosing its resource personnel each

community must consider these factors and access and modify resource responsibilities according to what is available and what best matches their priorities.

The idea of possibly having a member of the community in the position of ECIP staff did arise during the course of the study. The precedent for this has been made by Bloom (1978) for non-Indian communities. This option could facilitate not only ongoing adaptations of intervention strategies, but could also lead to better communication between other service professionals and the family, an issue of concern for participants. As well, participants thought it was important to have feedback from the community go to other professionals with respect to the appropriateness of the suggestions in relation to the child's environment. The whole community may also be more accepting of and have greater confidence in one of their members filling this particular role. Participants had mixed feelings about the likelihood of finding an individual in the community who they felt would be able to fulfill this role.

Formal Systems

Formal systems of support as defined by Roberts (1990) include those service providers who have been designated by society to provide services of one kind or another. This definition includes both Indian and non-Indian formal systems. Study participants shared some concerns about the usefulness of some of the non-Indian formal systems they or family members have encountered. They identified barriers to accessing the formal system which included:

- (1) lack of information about services in general;
- (2) individuals did not always see the relevance of the service they received;
- (3) personal beliefs about the causes of the problems were often different than those of the service providers and;
- (4) recommendations made were not appropriate to the individual's daily life experiences or those of the family's.

When supports and assistance do not match family or the community's needs, the child and family become vulnerable, and intervention can have more negative than positive effects (Dunst & Trivette, 1987; Gallagher, 1990). Services which are able to bridge the gap between

family needs and support services are those which ensure that services are relevant to cultural patterns and are thus said to be culturally competent (Cross, 1989; Pence et al, 1992; Roberts, 1990). Jean's personal experiences with the formal system seem to exemplify the need for supports and assistance to both match the family's needs and be culturally competent.

Many of the services in the non-Indian formal system have begun to shift their perspectives to that of the families they serve. They are becoming family focused services, ones which support the family in developing the ability to exercise control over the content and delivery of the services each receives (Dunst et.al., 1987; Vincent et al., 1990). Many formal systems are also adopting an "ecological" perspective which looks at children in terms of the environments in which they are growing and developing (Dunst & Trivette; Pence, 1992; Vincent et.al., 1990). Such service delivery systems are emphasizing the dynamic, interactive relationship between the child, the family, and the environment.

These changes will encourage the formal system to assume responsibility for the delivery of more and more culturally competent services. The addition of community-based programs which help bridge the gap

between traditional practices and the non-Indian formal system, are more likely to mesh the culture of a family with other agencies providing services, and foster an ongoing creative collaborative process.

The individual formal systems together make up the service delivery system. Concerns regarding the availability and accessibility of the service system were brought forward by study participants. Some concerns have already been discussed. Additional concerns included:

- (1) geographic isolation and travelling distances (some families were required to travel up to six hours one way for appointments);
- (2) disruption of the family routine (time away from work for one or both parents, arranging child care for other children in the home) and;
- (3) limited flexibility on behalf of the formal systems (appointment times were set without prior consultation with the family).

In a province such as Saskatchewan, geographic isolation and travelling distances is a reality which poses a challenge to both families and the service delivery system. Efficiency of service provision could be enhanced by better interagency coordination. Ways in

which this could be done include:

- (1) coordinating appointments to minimize the number of times a family must travel;
- (2) avoiding duplication of services by sharing information between agencies and professionals to minimize the need for unnecessary re-assessment, and by;
- (3) encouraging more consultation and collaboration among professionals.

Another factor to consider when looking at the effectiveness of service delivery system is to examine what kind of a system has evolved. As Harbin and McNulty (1990) write, the human service system is perhaps not really a system, but rather a collection of individual, political and specialized agencies from which families are to obtain appropriate services. This conclusion is supported by comments which Bob made in regards to the difficulties he encountered when trying to meet his son's needs.

In addition, certain services within the service system also suffer from what Boshier (cited in Harbin and McNulty, 1990) refers to as professional narcissism. In these, people believe that their perspective or the way in which their agency provides services is the only right way. These too, then, become significant barriers

for families, not allowing individuals to take control of, or the responsibility for, decision-making. Being excluded from the power of decision-making directly affects parents and the well-being of their families.

Studies have confirmed that service integration and/or coordination has a positive effect on accessibility, continuity and efficiency of service provision (Harbin and McNulty, 1990). Participants in the study did not feel that services were well coordinated, and subsequently this lack of coordination made things more difficult for families, at times, adding to their stress as opposed to minimizing it. The challenge that exists for the service delivery system is to determine how coordination of services could best occur in addition to recognizing the critical component of involving caregivers in a meaningful way in the planning and coordination of those services. In other words, the significant question which service delivery systems must address is: Can the service system become more user friendly?

Professional Practice

Professional practice has an impact on how the non-Indian formal system is perceived and used. Participants in the study community had difficulties in dealing with certain professionals. Their concerns were ones which are fairly common for many families who have children with handicaps, such as feeling intimidated, and lacking the confidence to express concerns or question recommendations.

As participants outlined, facility-based professionals tend to focus on the individual child, whereas the family may be focusing on the needs of the entire family and how they are accepted in the community. Intervening only with the child may be inappropriate if the culture of that family values modeling or less structured approaches. Ultimately such an intervention would not be in the best interest of the child and family. In the study community, extended family members often assume the role of primary caregivers. Yet the service providers only involve the biological mother and/or father. Such a practice may, in fact, alienate the very members in whom the family has vested the primary caregiver authority.

Bailey (1987), Turnbull and Turnbull (1986), Dunst

et.al. (1987), Gallimore et.al.(1993) and others have concluded that disagreements between parents and professionals over goals or methods of service delivery usually emerge because of differences in values, beliefs, and life experiences. Service providers must therefore also understand and take into consideration the "ecology" of the family. Change in the child is dependent not just on professional skills or the child's disability, but also on the complex interrelationships among family values, intra and extra family supports, and the match between services offered and perceived needs and wants of the family (Dunst et al., 1987). Jean was aware of this mismatch and often felt that recommendations which were made for her child were inappropriate and not useable in her family situation.

Practice issues that have an effect on service delivery to Indian families are also cross-cultural issues. Cross-cultural issues include historic distrust, language and communication behaviours, maintenance of stereotypic images, and ethics and rules of behaviour (Cross, 1989; Brant, 1990; Connors, 1988). The history of the relationship between two cultures often becomes part of the hidden baggage which individuals bring to the helping relationship (Cross, 1989). When service providers are unaware of historic distrust, they do not

know how to work through this issue and tend to misinterpret it as resistance. Equally, if service providers are unfamiliar with customary patterns for speech, turn-taking and communication etiquette, they will not be able to communicate effectively. Service providers may have unrealistic impressions of Indian people and stereotypic ideas of their lives (Cross, 1989).

Even when well intended non-Indian professionals learn more about a culture, there is still a tendency simply to replace old stereotypes with new ones and treat individuals as a homogeneous group (Cross, 1989). As the participants suggested, Indian ethics, values and rules of behaviour strongly influence Indian thinking and action. The service provider's failure to recognize how an individual's cultural heritage affects his behaviour, may result in misinterpretation and unperceived errors in intervention (Brant, 1990). Professionals must respect and support the rights of the family without intruding on private and deeply felt beliefs (Roberts, 1990).

Because we read a book, attend a workshop, or happen to be a minority person, it does not make us or the system we work in culturally competent. Rather, becoming culturally competent is a dynamic process where

we accept that people are from different backgrounds, make different choices and evaluate needs based on culture (Cross, 1989). How successfully we deliver services in the formal system is dependent to a great extent on our awareness and acceptance of differences in communication, life-styles, and definition of well-being and family.

FUTURE CHALLENGES

This thesis has given us some insights into a community's perspective of the needs of children and their families. There are two challenges which emerged from this study. The first is for the exploration and development of parental practices based on traditional values, but relevant to, and adapted for, dealing with the influences of today's world. The second challenge is for the community to take on the primary responsibility for child welfare matters. The community is in the position of developing a new knowledge base from which it could create a model for protecting children which remains consistent with traditional values and the dynamics of Native families. By protecting Native children, the community is also protecting and strengthening the integrity of Native culture.

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