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A STUDY OF THE DEPENDENT HANDICAPPED

by

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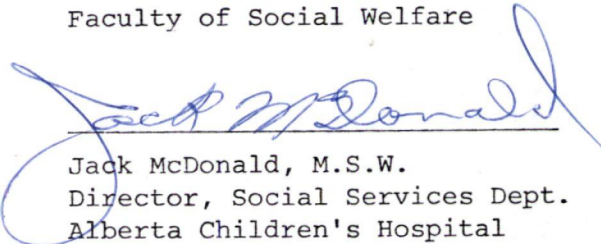
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## DEDICATION

To my husband, Greg, for his encouragement  
and to my daughter, Brianna, who taught me  
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## ABSTRACT

The purpose of this study is to identify the needs of the dependent handicapped who also have extensive health problems and to identify attitudes to the philosophy of normalization.

These needs and attitudes are identified in terms of how they are perceived by community representatives and parents of the dependent handicapped.

The study traces historical and philosophical attitudes towards the handicapped and identifies how these affected past care of this population. Details of service delivery in other countries is documented and described in terms of their impact upon Canadian services.

The needs and attitudes of the dependent handicapped are determined by the community representatives through a community planning process - the Calgary Plan.

The needs and attitudes, determined by the parents are collected through a questionnaire designed and administered to a sample of parents. The parents are those who have children registered with Handicapped Children's Services, Calgary Division, and who are classified as severely or profoundly retarded with extensive health requirements. Using the findings from these two groups a comparative analysis of the needs of the dependent handicapped is described.

The implications reveal certain areas of concern as well as possible future considerations in the planning of service for this population. Some conclusions in terms of present thinking towards normalization is included.

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## CHAPTER I

### INTRODUCTION

Mental retardation, as a handicap, continues to be one of the most debilitating and misunderstood disorders today. Historically it has been viewed as an unchanging and incurable condition with service being based on these attitudes.

Today, however, attitudes are slowly changing and many of the retarded are now seen to have potential for treatment and training. Many are able to lead productive lives and others can function well in sheltered settings. This study does not focus on this level of the mentally handicapped, rather its emphasis is on a specific portion of those who are severely to profoundly retarded. It is estimated that this group of severely and profoundly retarded comprise .1 per cent of the total population with approximately 523 located in the Calgary region.<sup>1</sup>

This group, in some ways, is the most controversial of any of those who suffer from retardation. The debate is still prevalent on whether they are unchanging and incurable or possess potential for treatment and training.

Many definitions for mental retardation have been proposed, however current useage favors the one used by the American Association of Mental Deficiency. Mental retardation is "subaverage general intellectual functioning which originates during the developmental period and is associated with impairment in adaptive behaviour."<sup>2</sup>

This definition encompasses a broad range of deviance from minimal to profound and is generally associated with four levels of functioning: I - minimal - Binet I.Q. range from 53-68; II - moderate - Binet I.Q. range from 36-52; III - severe - Binet I.Q. range from 20-35; IV - profound - Binet I.Q. range below 20.

Services for the retarded are generally based on the levels of functioning impairment in adaptive behaviour and age as opposed to the etiology of the retardation. The severely to profoundly retarded (those referred to in this study as Level C) are severely impaired in all levels of functioning.

This study will focus on Level C which in addition to their mental handicap have extensive health care needs. Extensive health care needs are defined by the "levels of handicap grids" developed for the Division of Services for the Handicapped, Calgary. This grid classifies the mental retardation population by level of mental ability, level of secondary handicap, and by age. Each grid identifies the handicapped individual's needs by describing his/her level of functioning in five major areas of dependency:

SUPERVISION AND CARE:	Staff supports needed because of medical status and health care requirements.
MOBILITY (MOTOR):	Staff and physical supports required because of physical handicap.
SOCIALIZATION/COMMUNICATION:	Degree of staff and program supports needed because of awareness and interaction with environment.
DEVELOPMENTAL SKILLS:	Degree of staff and program supports needed because of degree of self help and age relevant life skills.

## BEHAVIOUR:

Degree of staff and program support needs for control/training because of behaviour problems.

Each of these areas have been divided into five levels of functioning using the following general criteria.

Level 0 - no additional support required except as would be needed by the rest of the community.

Level 1 - could or can with some short term support use generic services.

Level 2 - requires specialized program/support to function within community.

Level 3 - requires extensive program and support to maintain daily routines.

Level 4 - requires extensive support to maintain life functions.

As a result of this kind of classification an individual's program needs are fairly specifically recorded. The synthesis of this information has resulted in the following categories of program needs:

- I Individuals who are mentally retarded with no other specific handicap.
- II Individuals with extensive physical handicaps (mobility level 3 or 4).
- III Individuals with extensive health care requirements (supervision and care level 3 or 4) and individuals with extensive personal care requirements (i.e. both health care and mobility requirements at level 3 or 4).
- IV Individuals with severe behaviour problems (behaviour at level 3 or 4).

The three levels of "Mental Handicap" are indicated with each of the above groups. The rationale being that different types of programs needed to be developed depending on the level of mental handicap. The levels of mental retardation are as follows:

- A. Mild Mental Handicap - those persons who as children can frequently be found in the regular school system but who may require some additional support at some point in their life.
- B. Moderate Mental Handicap - persons who usually require specialized training, support or family routine to function within the community.
- C. Dependent (Severe to Profound) Mental Handicap - persons who generally require extensive support and assistance in self care and daily routines. These persons have traditionally been found in institutions or extended care facilities.

Therefore, the population in this study can be described as the dependent handicapped (Level C) with extensive personal and health care requirements (Category III). These number 79 in total. Of this population 10% are still at home, 80% are in institutions, and 10% in extended care facilities.<sup>3</sup>

In reference to this study, the following objectives are set out:

- (1) To describe how the needs of the mentally handicapped population were perceived historically by studying the ideologies and resultant human management models that existed during different time periods.
- (2) To examine the generic service delivery for the handicapped in other countries and how this service had an impact upon Canadian services.
- (3) To describe the needs of the study population as perceived by members of a community planning process under the auspices of the Division of Services for the Handicapped of the Department of Alberta Social Services and Community Health in Calgary.
- (4) To survey the needs of this population as perceived by the parents in relation to programming and residential services.
- (5) To compare the differences and similarities between the parents' perception and the community's perception of the needs of this population and the implication of this on service delivery.

Each of these objectives will be described in five separate chapters with a final chapter discussing the implications of the results of the study.

## NOTES TO CHAPTER I

1. Perry Kinkaid, "Residential Training Facilities for the Dependent Handicapped," A Presentation to the Cabinet Committee on Social Planning, Edmonton, June 16, 1976, mimeographed.
2. American Association on Mental Deficiency, A Manual on Terminology and Classification in Mental Retardation, Willimantic, Connecticut: The Association, 1961.
3. Department of Alberta Social Services and Community Health, Technical Supplement - Division of Services for the Handicapped, Calgary, Alberta: The Department, December, 1977.

## CHAPTER II

### HISTORICAL BACKGROUND

In this chapter the writer will examine how the needs of the mentally handicapped population were perceived historically by studying the ideologies and resultant human management models that existed during different time periods.

Historically, the retarded have been viewed from many different perspectives. These perspectives or ideologies have largely determined man's behaviour towards this population. An ideology has been defined by Wolfensberger as a "combination of beliefs, attitudes, and interpretations of reality that are derived from one's experience, one's knowledge of what are presumed to be facts, and above all, one's values."<sup>1</sup> Ideologies can therefore be described as the forces that determine many behaviours. If human management ideologies have widespread implications and are expressed consistently they are often referred to as human management models. Therefore management behaviours, social organizations of service systems and manpower practices are usually consistent with their management model.

In discussing human management in relation to the retarded it is necessary to look at the concept of deviancy. The literature reveals this concept as the ideological framework underlying the historical management of the retarded. "A person can be defined as deviant if he is perceived as being significantly different from others in some overt aspects and if this difference is negatively

valued. An overt and negatively valued characteristic is called a stigma."<sup>2</sup> It follows that the retardate who is handicapped is therefore stigmatized as a deviant according to this definition.

Historically, retarded people appeared to be grouped with other types of deviants or defectives such as beggars, criminals and the blind. Society's reaction to deviancy went through several periods of change. Wolfensberger cites four historical reactions to deviancy, i.e.:

1. Deviancy is preventable. This perspective incorporates removing the negative value of differentness.
2. Deviancy can be undone through such means as training, education and treatment.
3. Deviants should be segregated. By the nature of their differentness society must be protected from the deviant or at least sheltered from constant exposure. This philosophy is still reflected in our present system in terms of treatment of minority groups such as Indians and the aged.
4. Deviance must be eliminated. This philosophy has self-preservation and protection as its base. In earlier times this philosophy appeared to have linkages with the devil and evil, where differentness had to be persecuted and destroyed. In present society there are overtones of this idea in various cultures which reinforce the destruction of weaker beings eg. Eskimos.<sup>3</sup>

The retardate was viewed as a deviant, however, the perception of the deviant role played by the retardate was the link that determined the kind of institutional models that evolved. The literature was abundant with many role perceptions of the retardate; not all roles, however were perceived as being deviant. Wolfensberger cited seven major roles attributed to the retarded.<sup>4</sup> This writer has expanded upon these roles that have been set out by Wolfensberger.



### The Retardate as a Sick Person

One of the more common roles of the retardate is that of a sick person. This role carries with it the medical model of treatment with residential facilities structured according to the hospital principle. This has definite implications on the staffing and administrative management. Both are generally orientated on the "sick" concept rather than on health and normalization concepts. The retarded are cared for on nursing units or wards. Routines are established on a hospital basis. Rounds are made by the doctors and the general care is maintained by institutional aides with consultation provided by the nursing staff. Little emphasis is placed upon rehabilitation or recreational therapy. Patient needs are generally secondary to staff and organizational needs, for example, feeding schedules generally following shift changes rather than patient needs. The dispensing of medication is a major part of the patient program and the emphasis is on subduing and restricting behaviour rather than training.

This particular approach to retardation poses certain problems.

On the one hand, such a conceptualization often results in pursuit of treatment hoped to result in a "cure"; on the other hand, unless a "cure" is seen as likely, the management atmosphere is often permeated with hopelessness and treatment nihilism. In other words, the sick conceptualization tends to be correlated with inappropriate extremes of management attitudes.<sup>5</sup>

### The Retardate as Subhuman

This role carries with it definite expectations for care. Generally the retarded is thought of as an insensitive and dehumanized animal and the care afforded him is on the basis of this perception.

Basically the retarded have no rights under this framework. They are cared for in much the same way as animals. The literature is rich in its description of this role of the retarded.

Dehumanization of the retarded is so accepted, even to this day and even by workers in our own field (i.e. the field of mental retardation) that we witness a public statement by a contemporary superintendent of a state institution referring to retardates as so called human beings . . . below what we might call an animal level of functioning . . .

This attitude towards the retardate carries definite implications in terms of institutional behaviour as well as the kinds of facilities that are developed. Facilities are usually designed to be "abuse-resistant" and easily controllable. Locks, bars and fences are not uncommon, nor is segregation. Little control is given to the retardate over his own activities or environment and thus again the stress on control and supervision. This has a direct effect upon the size and lay-out of the residential facility. Little interaction, high emphasis on drugs and isolated location for residential centres are not uncommon in this model.

The lack of programming, education and training is seen as appropriate as the retardate is seen as incapable of learning. Environments are therefore geared to maintenance not to opportunity.

#### The Retardate as an Individual to be Pitied

Associated with this model are ideas of suffering, lack of accountability, protection, shelter from growth and development. Wolfensberger associates this with "infantilization." The "pity model" tends towards a dehumanization principle although there is a sharp difference in terms of the attempts made to create a happy environment. Facilities also reflect this "happy" principle in terms of program and space.

### The Retardate as an Object of Charity

This model incorporates all the traditional stigma of charity and revolves around minimum basic need fulfillment with little provision for enrichment as this would exceed the basic requirements. There is an emphasis on the retardate helping himself in terms of work, as well as an expectation that he be grateful for what he has.

### The Retardate as a "Holy Innocent"

This role carries with it an emphasis on "specialness." The retardate has often been perceived as a child of God under this model. Ideas of harmlessness, indulgence and integration are common. Integration is quite significant in terms of incorporation into the community. This has an effect upon facilities in terms of options to the large institutions.

### The Retardate as a Developing Person

This model follows certain "normalization" principles. Normalization has been simply defined as "letting the mentally retardate obtain an existence as close to normal as possible."<sup>7</sup> It is significant to clarify that normalization does not imply making handicapped persons normal, rather its emphasis is on the provision of a normal environment in accordance with assessed needs.

Several principles are essential in providing a good developmental-normalization model. Special attention will be given to outlining these principles due to the emphasis placed on normalization in this study. The additional emphasis devoted to these principles can be studied differentially depending on the level of mental retardation. The following content is intended to provide a generic

framework for the reader in terms of some basic normalization thinking. Chapter VII will articulate more clearly how some of these principles apply specifically to the dependent handicapped.

Under normalization guidelines physical and social integration are encouraged. Integration into normal society is probably the most important principle in achieving normalization under a developmental model. Integration holds as its opposite such variables as segregation, isolation, depersonalization and rejection, which most other role models share.

Through careful planning it is possible to integrate handicapped persons into society both physically and socially by providing opportunities: 1) to have the same wide variety of life experiences as the majority of people; 2) to have easy and frequent access to highly valued peer models; 3) to have continuous exposure to normal expectations and demands; 4) to experience a sense of autonomy, and the joy of personal choice; 5) to meet many people and to form friendships; 6) to appear normal and to feel normal among other people; 7) to avoid segregation and isolation; and 8) to make a contribution to society. These are some of the benefits which tend to flow naturally to handicapped persons when they are integrated into society<sup>8</sup> and are able to participate in the life of a community.

Integration, under the normalization principle has both physical i.e., environmental components, and social components. Physical integration stresses community residential services. This implies location of residential services within a community and not on the periphery as well as accessibility to families, work opportunities, and staff. Residential facilities should be located near opportunities for social integration such as schools and theatres.

An important guideline in physical integration is the avoidance of "overload", i.e., a spacing of the number of handicapped persons in one area in order to facilitate maximum absorption into the community. In addition residential buildings should carry a low profile in terms of labelling and appearance for the same reason.

An essential prerequisite for social integration is physical integration. Two important aspects of social integration are contact with non-handicapped people as well as good staff selection. Non-handicapped people offer an opportunity for "image transfer" i.e., the status of handicapped persons is often improved through good staff selection as opposed to hiring residential care people who are themselves devalued as people.

The developmental model therefore implies a capability for growth as well as a positive attitude towards the modifiability of behaviour.

The six role models of the retarded as set out above are by no means exhaustive. They do begin, however, to provide a basis for looking at the historical residential management approaches to this population and to provide a starting point for looking at society's efforts to handle deviancy. Wolfensberger has conceptualized society's management of the deviant retarded into three major groupings. These groupings are reinforced by the literature in the field, they are:

- A. 1850-1880 - Making the Deviant Undeviant
- B. 1870-1890 - Shelter the Deviant from Society
- C. 1880-1925 - Protect Society from the Deviant<sup>9</sup>

#### A. Making the Deviant Undeviant

The initial period from 1850-1880 has been labelled "making the deviant undeviant" and it is associated with a limited developmental role model of the retardate. This period placed an emphasis on education and training. Wilbur's statement appears to adequately sum up the philosophy of the time:

. . . We do not propose . . . to bring all grades of idiocy to the same standard of development or discipline; nor to make them all capable of sustaining credibility . . . but rather to give to dormant faculties the greatest practical development, and to apply these awakened faculties to a useful purpose under the control of an aroused and disciplined will.<sup>10</sup>

This is further reinforced by Seguin, a pioneer in the field of mental retardation for over thirty years, in his statement:

Idiots have been improved, educated, and even cured. Not one in a thousand has been entirely refractory to treatment, not one in a hundred who has not been made more healthy, and happy.<sup>11</sup>

During this period the institution was seen as a school which was set up to provide special training. This training was looked at as a temporary measure with the return of the retardate to the community as the ultimate goal. The institution was definitely not perceived as a custodial lifetime living arrangement.

There were efforts however, during this time to distinguish between the levels of retardation and only the most promising were taken into the school setting. This philosophy was documented by Horne in 1852 in his statement . . . "The most favorable subjects for training, as a general thing, are those who enjoy good bodily health, who are free from epileptic and other fits, and whose heads are not enlarged."<sup>12</sup>

Several other principles were prominent during this period. The most noticeable being the organizational and management philosophies. Institutions were organized as closely as possible on a family module with a stress on interaction between handicapped and non-handicapped. The kind of assistance given was not looked at as charity but as a right.

#### B. Protecting the Deviant from the Nondeviant

Around 1870 the tide began to change. This change was stimulated by several factors. The developmental model, which stressed training was carried to the extreme of rehabilitation and re-integration by the people of the time. This carried the seeds of its own destruction; as a natural consequence of attempting training and rehabilitation for this population would mean that some would fail to achieve this goal and others, by the very nature of their handicap would require long term care. As a result of this failure to meet the ultimate and ideal, the developmental model was abandoned and the attitude shifted to one of pity and protection. This is reflected by C. T. Wilbur in 1880:

In the race of life, where an individual who is backward or peculiar attempts to compete with those who are not, the disadvantages are so great that the graduate from the idiot asylum really has no chance to succeed. The capacity of the individual is not at fault; but the world is not full of philanthropic people who are willing to take the individual from the asylum and surround him with proper guardianship which his care demands.<sup>13</sup>

This attitude was reinforced by Johnson in 1889 in his statement: "They must be kept quietly, safely, away from the world, living like angels in heaven, neither marrying or given in marriage."<sup>14</sup>

A kind of idyllic picture is reflected throughout the literature of the time:

Here and there scattered over the country, may be villages of the simple, made up of the warped, twisted, and incorrigible, happily contributing to their own and the support of those more lowly,--- 'cities of refuge,' in truth; havens in which all shall live contentedly, because no longer misunderstood nor taxed with extractions beyond their mental or moral capacity.<sup>15</sup>

Schools began to be replaced by asylums, that were both custodial and hospital-based. This shift is reflected by Butler in his statement in 1883 . . . "Give them an asylum with good and kind treatment; but not a school."<sup>16</sup> Wolfensberger points out three dangerous trends during this period in terms of isolation, enlargement and economization.<sup>17</sup>

Isolation was based upon protection from the non-deviant and his ridicule. Enlargement occurred as a result of what was interpreted as the optimal structure to give good service and meet the needs of all the population both trainable and untrainables. The philosophy of the time also reflected a kind of positiveness in the retarded associating with other retarded and protecting them from excessive exposure to non-handicapped. It was at this time, also that the economic factors began to be of some concern and the planners of the time began to see the cost advantage of congregating large numbers of handicapped together. The advantages of having the retarded work and contribute to his own keep was initially proposed on the basis of treatment and relief from idleness. This attitude gradually gave way to the economic value of this work to the institution. This in turn contributed to the growth of institutions for the sake



of agricultural productivity. Isolation occurred as a result of the size needed to achieve this.

The pity era set the pace for the next period in which suffering and charity were replaced by brutalization.

C. Protecting the Nondeviant from the Deviant

This era began around 1880 and is characterized by an increasingly negative attitude towards the retarded.

This is reflected by such writers as Wilmarth and Johnson:

My child your life has been a succession of failures. You cannot feed and clothe yourself honestly; you cannot control your appetites and passion. Left to yourself, you are not only useless, but mischievous. Henceforth, I shall care for you.<sup>18</sup>

Is there anything more worthy the thoughtful attention of the statesmen of our land than to improve our methods of support of the weak ones so that we may add to it the needed element of 'control?'<sup>19</sup>

This kind of attitude became more entrenched as the 1900's progressed.

It is indicated in such statements as those of Goddard in 1915:

For many generations we have recognized and pitied the idiot. Of late we have recognized a higher type of defective, the moron, and have discovered that he is a burden; that he is a menace to society and civilization; that he is responsible to a large degree for many, if not all, of our social problems.<sup>20</sup>

This kind of ideology reinforced the dehumanizing practices in the care of the mentally retardate. This culminated in a fear of the retarded as a menace which brought with it a concern for prevention. Attitudes such as those reflected by Knight were not uncommon:

"At least, let up wipe out the stain of legalizing the production of idiocy, imbecility, insanity and crime."<sup>21</sup>

In attempting to weigh the impact of some of these statements it is important to keep in mind that many of the persons quoted such as Wilbur, Knight, Johnson and Goddard were presidents of Associations for the Mentally Deficient in America and were thus in a position to exert considerable public influence towards the retarded.

This negativism was further enhanced by several occurrences. One of the main occurrences was the results of several studies done on the retarded where the researchers became convinced of heredity as a causal factor in retardation. This encouraged the segregation of the retarded, particularly those who were capable of reproduction. Robert Dugdale published a genealogical study in 1877 which was entitled The Jukes: A Study of Crime, Pauperism, Disease, and Heredity. Through this study Dugdale traced the descendants of two brothers married to two sisters. Dugdale did not label the family as mentally deficient although this was implicit in his work. A follow-up study was conducted in 1915 by the Department of Experimental Evolution of the Carnegie Institute at which time every known Jukes was contacted. The result of this research was summed up in the statement, "not all feeble-minded Jukes are criminal, but all Juke criminals that I have known, I regard as mentally defective."<sup>22</sup>

This concern regarding eugenics was intensified with a study done by H. H. Goddard in 1912 titled the Kallik Family.<sup>23</sup> The study traced the descendants of one feeble-minded son who was the offspring of a normal father and a mentally retarded mother. Of the 840 descendants traced, 143 were labelled subnormal and 46 proved to

be normal and self-sufficient. The relationship of retardation to heredity and crime was generally an attitude of the times and had the effect of moving public sentiment from one of pity towards the retarded to viewing him as a menace to society.

Another effector of this attitude was the increased useage of mental tests which simplified recognition of mental defects. The effect of this was to contribute to a panic in terms of the possibilities of the retarded reproducing at a greater rate than the non-retarded.

This kind of alarmist attitude reached its peak in such statements as those made by Johnson in 1901 . . . "I do not think that, to prevent the propagation of this class it is necessary to kill them off or to resort to the knife; but, if it is necessary, it should be done."<sup>24</sup>

The economic and political thinking of this time was congruent with the attitude towards the retarded. The emphasis on individualism, survival of the fittest and competition was prominent.

Belief in the genetic causation, of retardation had some convenient aspects. By proposing that most social problems would be solved if the poorer members of society would stop having children, one could feel freed from a sense of responsibility for bad social conditions. Furthermore, one was relieved from the worry of the effect of slum conditions upon children, if one could believe that many such children were genetically inferior to begin with. It is probably no coincidence that (this) period overlapped with periods during which Social Darwinism and laissez-faire socio-economic policies were prominent.<sup>25</sup>

The attitudes of the time had a direct effect upon the kind of care and programming that evolved during this period. The mandate for programming was prevention. Several different means of achieving

this goal were attempted and each met with failure. These failures were in the areas of preventive marriage laws, preventive sterilization and preventive segregation. Preventive segregation carried with it the necessity of large scale institutionalization and it was to this end that the planners in the field attempted to move during this period. This was accompanied by a decrease in funding on the part of the legislators. Thus, the situation called for large scale expansion but with a cutback in funds. The result being that many of the less severely retarded began to labor in the institution in order to reduce costs. This labour eventually turned into exploitation. Additional measures saw the reduction in costs occurring as a result of an increased population. This attitude was summed up adequately by Johnson in 1902:

The only hope that I can see of the state taking complete care and responsibility of all idiots and imbeciles is that all of the higher grade . . . shall be so usefully employed that they may be practically self supporting. We need a great deal of low grade labor, and a great deal of labor can be performed by laborers of a low degree of intelligence. In the care of the lowest custodial grade of imbeciles, in the care of epileptics of low grade, there is a great deal of labour available among our trained imbeciles; and they can do better work than to exercise such care in an institution.<sup>26</sup>

Thus the emphasis of the time was that of self-sufficiency for the retardate through his own labor. To this end, institutions continued to take on a grand scale. Residents were often worked beyond their capabilities and this was rationalized on the basis of helping them to mould good behaviour and preventing them from engaging in bad behaviour due to fatigue. Medical care at this time was poor if existent at all. This economization attitude extended itself not only in everyday operating procedure of institutions but

to the actual buildings themselves. Anything more than the bare necessity in terms of buildings was looked at as an extravagance and beyond the appreciation of the retarded. It became increasingly evident how many of the rationalizations for the lack of care began to emerge in relation to this population.

Large scale institutions enhanced segregation and it became necessary to locate facilities away from the community because of their size. Thus the retarded became more isolated than ever.

It becomes evident when looking at this period how the present trends in our institutions emerged. The isolation, segregation, vastness, economization and non-rehabilitative aspects are an intricate part of institutional life today and are only now receiving attention from planners in the field who see normalization and community options as the answer to some of the historical problems in residential care and service for the retarded. There was no thought given to these alternatives at this time nor to such measures as subsidization to a family in order to help them maintain their child in the home.

#### D. The Normative Period

Although Wolfensberger has conceptualized three time frames in reference to the management of the retarded, it is proposed by this writer that a fourth may now be added. This could be termed the "Normative Period" where the current emphasis is on the maintenance or attainment of normative behaviour. Much has been written on normalization. Originating in Scandanavia with Bengt Nirje and Bank Mikkelsen this concept has gained prominence in North America

through the efforts of Wolf Wolfensberger. Several philosophical principles of normalization have been described under the "developmental role model of the retarded"; however Nirje's definition of normalization covers several additional points.

Nirje cites eight essential points of normalization:

1. Normalization means a normal rhythm of day for the retarded.
2. The normalization principle implies a normal routine of life. Most people live in one place, work or attend school somewhere else, and have leisure time activities in a variety of places.
3. Normalization means to experience the normal rhythm of the year, with holidays and family days of personal significance.
4. Normalization also means an opportunity to undergo normal developmental experiences in the life cycle.
5. The normalization principle also means that the choices, wishes, and desires of the mentally retarded themselves have to be taken into consideration as nearly as possible, and respected.
6. Normalization also means living in a bisexual world.
7. A prerequisite to letting the retarded obtain an existence as close to normal as possible is to apply normal economic standards.
8. An important part of the normalization principle implies that the standards of the physical facilities e.g., hospitals, schools, group homes, hostels, should be the same as those regularly applied in society to the same kind of facilities for ordinary citizens.<sup>27</sup>

Gunnar Dybwad, another pioneer in the area of mental retardation has expanded the normalization principles to the program area on three particular levels:

1. On the first level, a deviant individual, in our case a mentally retarded person, should be enabled to behave in such a fashion that he will be perceived as non-deviant or at least less deviant.
2. On the second level the main task is to interpret the deviant person to others in such a fashion as to minimize his difference from and maximize his similarities with them.
3. On the third level of programming for normalization, emphasis is on moulding attitudes of the public so as to make it more accepting of deviancy in general, including deviancy in intelligence, education, <sup>28</sup>appearance, manners, dress, grooming, speech etc.

Dybwad also discusses the four related concepts of integration, dispersal, specialization, and continuity in reference to residential services that are planned under normalization guidelines. Integration is both social and physical and refers to measures which maximize a retarded person's integration into the community. Dispersal encompasses efforts made against "overloading" a community i.e., not congregating too many deviants in numbers larger than can be absorbed by the community. Specialization of specific residential functions is essential with the mentally retarded as all categories of retardation cannot be cared for by one service; nor do the mildly and profoundly retarded have the same needs in terms of service. This concept carries implications in terms of the development of a community based network of services, as well as the differential application of the normalization principles.

Continuity is also essential in achieving normalization. Continuity is twofold; it encompasses the availability of services as well as the link which exists between those aspects of a person's life that are supported by special services and the others which are not.

The beginnings of this philosophy can be seen as early as 1918 in such statements as those by Taft:

When by segregation we mean a fairly complete shutting off from society of all feeble-minded, including the higher grade types, we ignore a profound aversion on the part of people in general to confinement for life of any human being, particularly when no offense has been committed commensurate with such punishment and when the individual to be segregated seems to the ordinary observer not to be very different from himself. This, combined with feelings which relatives, particularly of the high grade feeble-minded have against segregation, makes a very complete program of this kind quite impossible for some time to come.<sup>29</sup>

This kind of statement is indicative of the early roots of the community integration principles that are again being reflected in current literature. The present period, however, does appear to be dichotomous. Although the attitude to the retarded has changed from menace and brutalization to one of greater understanding, many of our present institutions are set up and deliver services based on old philosophies. Much of the "warehousing" manner of care is still in existence with some modifications coming in terms of the kind of philosophy and treatment within the institution. There does, however, still exist much denial of basic property rights; lack of training, stimulation, movement and communication; and control through medication rather than training.

This dichotomy and the struggle behind it is reflected in such statements as those of Dartington and Miller, two workers in the area of handicapped services:

It appears very difficult to cling to the reality that a physically handicapped person may be both heavily dependent on constant care and attention and, at the same time, capable of autonomous self expression. He has to be classified as either less than a whole person or else 'really normal.'<sup>30</sup>



It is evident that an entire institution can embody either one of these attitudes or a combination of both. There is, as yet, no complete philosophy in our society towards the management of the retarded that is reflected in the operating of the services which results in much general fragmentation of services for this population. This is further reflected in such studies as those done by Miller and Gwynne in 1972 where a number of residences were identified as operating a "warehousing" model. The emphasis here was physical care with no provision for development, independence and individuality. Other institutions which were labelled as being less common, operated on what was termed a "horticultural" model i.e., emphasis was on self-development and achievement. In both environments there was an emphasis on the rejection of the retardate by others and the use of the institution as a dumping ground. The conclusion from such studies indicate that society's attitude towards the handicapped encompasses an ambivalent set of attitudes which in turn is reflected in the management and care of this group.

This dichotomy is stressed, at a different level by Gunnar Dybwad:

Looking at the problem of change from a broader nationwide perspective, it seems that one can characterize the present development of mentally retarded services . . . somewhat as follows: although there has been widespread advocacy for increased emphasis on nonresidential services, need for residential services is perpetuated and reinforced by the placing of low fiscal priority on nonresidential services and a high fiscal priority on maintenance and construction of residential facilities. This results in a shortage of non-residential services, which, in turn, leads to an accentuation of the urgency for the

creation of additional residential services which are storing up an ever larger number of individuals, since those ready to return to the community cannot be released because of the inadequacy of the supportive nonresidential services--a vicious circle, indeed.<sup>31</sup>

Although, broadly speaking, there has been a lag between philosophy and service implementation many significant strides have occurred in the actual implementation of normalization. One of the most significant being that of increased understanding of the needs of the retarded in terms of such factors as financial aid, day care and relief bed space. These kinds of efforts have resulted in many more retarded being cared for in their own communities and homes. The literature is beginning to reflect an emphasis on community integration as reflected by Sarason:

To the extent that a plan for residential care does not reflect the systematic exploration of the alternative ways in which it can be related to other community needs and problems--that is truly integrated with the activities of diverse groups and settings in the community--to the extent the field of mental retardation and the larger social community will be robbed of the benefits they can derive from each other . . . As we enter a period in which new patterns of residential care are being seriously discussed we have the possibility, perhaps for the first time, of planning in ways which would make it possible for the field of mental retardation to affect the values, consciousness, and activities of the larger community. But this will be possible only to the extent that we concretize the difference between being physically in a community and being psychologically and socially a part of it.<sup>32</sup>

Concrete efforts to achieve this kind of community integration are occurring in countries such as Denmark, Sweden, Great Britain and the United States.<sup>33</sup> Efforts in Canada have been highlighted in Edmonton with the implementation of resource centres for the

dependent handicapped in Edmonton. This community integration principle is reflected by Kinkaid in his presentation to Cabinet:

A Working Committee established in the fall of 1973 assessed the need and proposed the immediate development of five resource centres in the City of Edmonton over the next four years to accommodate 100 dependent handicapped persons and to provide day programs for this number and an additional 50 persons living at home.

The five resource centres will serve as a regional network for residential, training and family support services for dependent handicapped persons thereby supporting family ties and involvement.

### Summary

Although the efforts towards community integration and normalization are by no means complete or universal they do represent an emerging trend in the management of the mentally retarded. In this chapter the writer has reviewed the historical management of the retarded in order to acquire an understanding of the ideologies that existed as well as an understanding of how these were translated into the institutional models of the time. It has concluded with a glimpse of the present situation particularly an elaboration of the current management philosophy as well as an emphasis of the existing lag between the philosophy and service implementation.

The information on normalization refers to mental retardation in general and it is the assumption of this writer that the acceptance of the philosophy is probably most evident with the mild and moderate levels of retardation. It is felt that the dichotomous issue will remain quite pronounced regarding the severe to profound levels and the application of the normalization principles will differ between

these groups and in all likelihood will be evident in the management models being advocated in Alberta, and which will be discussed in Chapters IV and VI of his project.

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### CHAPTER III

#### INFLUENCE OF OTHER COUNTRIES

In this chapter the writer will discuss service delivery in other countries and will examine how such service has influenced Canadian thinking.

Programming for the mentally retarded in other countries has had an impact upon the development of care and services for this population in Canada. Countries that have had a significant impact on the Canadian delivery system are Denmark, Sweden, Great Britain, and the United States. Although it is felt that cultural factors play a prominent role in the management of the retarded a comparative cultural analysis has not been included in this study.

Although the histories of the studied countries have been different, they have generally followed a similar trend in the treatment of the retarded. This trend has encompassed a movement away from institutionalization and towards a concept of greater integration into the community as well as an emphasis on the normalization principles. The normalization theory was first expressed through the literature by such men as Bank-Mikkelsen of Denmark and Bengt Nirje of Sweden. These men were the pioneers of normalization and this fact is reflected in the level of care in both their countries. Normalization, as a planning philosophy, was later adopted in the United States by men such as Wolf Wolfensberger and Robert Kugel. These men, in turn, have recently had a significant



impact upon Canadian thinking in terms of the present attention being directed towards normalization.

## Denmark

### Legislation

In 1959 the Danish government took legislative action in regards to care for the mentally retarded and other handicapped persons. This act established a semi-independent organization known as the Mental Retardation Service to provide care and planning for this population. This service was placed under the jurisdiction of the Ministry of Social Affairs.

### Administrative Structure

The service system is decentralized into twelve regions, each with its own administrative centre. These centres are linked to one main programming centre located in Copenhagen. The over-all administration of the service system is provided by a Board of Directors who work in liason with the regional centres.<sup>1</sup> The Board of Directors is responsible for administering the Act and the regional centers administer residential services within the area.

### Service Provision and Philosophy

A strong feature of the Danish program is that of compulsory education. Children who cannot be accommodated in the regular school setting are subject to compulsory training and education between the ages of 7 and 21. Compulsory service can be imposed on handicapped young persons under 18 years of age against the parents' request on consent of child welfare authorities. This decision, however, must be made by a Central Tribunal.<sup>2</sup>

Financing for the service is done on a national level and all retarded persons are registered both regionally and nationally. The registration has a secondary function of providing information on global client needs as well as providing a resource for research data.

The service system in Denmark is set up under normalization guidelines. It attempts to bring as much individual attention to each client as possible. To this end it is highly differentiated in terms of facilities and disciplines. A great deal of emphasis is placed on integration and the basic right of treatment and training.

Attention is also given to special care and support functions and especially the provision of relief beds. Relief beds are not located in large institutions but in smaller family type facilities to provide for continuity for the child.

Community support services are abundant. Day cares, family counselling and financial aid are only some of the services provided. In addition, the service assumes responsibility for the education and provision of babysitters. Recreational facilities as well as regular holidays are part of the program for the retarded.

Hostels and group homes are used by those adults capable of living in such facilities, and the maximum number of residents is generally 20.

Small units housing 8 children are being developed. The goal is integration into community schools.

Future trends in Denmark encompass a separation of children and adults as well as a greater emphasis on community services and home help.

The Danish model places a high priority on the multidisciplinary feature of service delivery. To this end, regional service units are administered by a four-man team composed of an administrator, a physician, a social worker and an educationalist.

The main centre for mentally retarded children's services is located at the Children's Hospital. Although labelled a "hospital" the centre encompasses a philosophy and planning model of deinstitutionalization. It incorporates a village-community concept, with all buildings being one storey high and all units having direct access to the outdoors. Dormitories are nonexistent and instead separate rooms for children exist. Each child has his own property and private areas for living. Clinical facilities and recreational facilities exist on the hospital grounds, but in separate buildings.

An educational facility is located in the centre of the children's home and special staff are recruited for these teaching positions and, unlike most other countries, the quality of education provided to this group is seen as a priority. This reflects the "total care" philosophy underlying Denmark's program.

Children and adult centres are separated, although they do share certain common facilities and interaction is encouraged. This is looked at as being essential in order to aid the transition to the adult centre once the child has completed his education or when he reaches adult age.

The central institution for adult services in the Danish model does not have all the innovations of the children's centre; however within a structurally reorganized institution, without the benefit of

creating a new facility, it does attempt to achieve the same goals as the children's centre. The adult centre functions as a hospital, training centre and home, particularly for the population requiring extensive medical and nursing care. This centre is really an adjunct to the group homes and hostels for those who are in need.

One of the principle guidelines is deinstitutionalization and as a result, hospital wards are limited and generally used only for short term observation and treatment. The rest of the residence consists of rooms where a resident can enjoy his privacy as well as his personal property.

#### Staff

A great deal of emphasis is placed on individual education and training and a great deal of care goes into the selection of staff for these tasks. It should be noted that accountability is encouraged and this provides the rationale for having educational staff report to the Director of Education, who in turn is a member of the administrative team.

Another interesting point in the Danish model is the special emphasis on the recruitment of good staff. The importance of this is emphasized in what is called the "Care Assistants" training program. This staff would be comparable to the Canadian "institutional aide"; however the background and training is vastly different. Institutional aides require no specialized training; whereas basic training for the care assistant lasts three years. The first three months consist of practical training in the institution where both employer and employee attempt to evaluate the candidate's suitability. If

successful, this is followed by 10 more months of practice. Thereafter, the theoretical education begins at the Personnel High School and lasts for five months, after which follows thirteen more months of practice. Training is concluded by a final examination. It should be noted that training content varies from physiological understanding to basic workshop training in the hope that the care assistant will be flexible enough in his knowledge to meet the needs of the resident.

### Sweden

#### Legislation

Sweden passed a new law for the mentally retarded in 1968. This law, had normalization as its orientation, and as a result is looked at as a Bill of Rights for the retarded which strives to ensure the individuality of meeting each client's personal needs. This law also stresses the provision of community services and as such holds integration as a major guideline. In this sense it widely differs from Sweden's previous law which focused mainly on residential institutions.

#### Administrative Structure

Administration of services for the retarded rests with the county councils, which is the local government body in Sweden. Part of Sweden's present philosophy is to have an integration of all health services at this level of government.

In terms of specialized facilities Sweden is undergoing change. At one time, all specialized institutional care was provided at the national level; however with increased decentralization and

therefore the increased need at the local level, the response has been to establish these facilities within the regions which form the middle area between the local and national levels. Sweden regards this move as rational and economical and sees the "functional interrelationship" between the levels as the key to a successful program.

The administration of the legislation for the retarded in Sweden has an impact upon the effectiveness of the programming. Implementation of this legislation is the responsibility of both the National Board of Education and the National Board of Health and Welfare. The two Boards have a joint membership of fifteen people from various disciplines who act as advisors and consultants. Planning is largely done at the county level, however, approval rests with the central authorities. The planning philosophy of Sweden, in terms of facilities, is geared to that of small residences for all levels of retardation with a back-up facility for specialized care for those in need of that kind of service.

The division of service on a local, regional and national basis allows for greater specialization in the Swedish model. At the regional level, specialized residential care is available. This care is closely linked with university and research facilities. The regional centre serves the local level by passing on new types of techniques, diagnosis and therapy. In developing regional centres several factors are generally taken into account to ensure that it will be able to meet its goals. Factors such as population, demography, number of clients, optimum facility size, location and availability

of specialists are felt to be significant variables in the success of a regional centre. A regional centre generally serves two types of needs, but a wide range of clients within these needs. Firstly, it provides long-term care facilities for those who require this kind of care because of their handicap and, secondly, those clients requiring short term care who need special personnel and facilities for study or treatment of a limited nature. Thus there is a free flow of residents between the local and regional levels.

In terms of implementation of regional facilities, the decision is made by member countries, however the ownership and administration is retained by the county in which it exists. Individual client responsibility is still retained by the individual counties. Thus, the Swedish model greatly relies on integration and co-operation between its three levels of government.

#### Service Provision

Community services such as day care and vocational workshops are looked at as a priority. In addition, many support services are offered to those families who choose to keep their children in their homes. Provisions for the choice of the kind of care, either inside or outside the home are also available for the family to consider. The Swedish people see the provision for independent living quarters for capable retardates as a progressive feature of their new law.

Compulsory education is also a feature of Sweden's program. Training is divided into two categories--the "educable" programs for the mild and moderate retardate and the "trainable" programs

for the moderate and severely retarded. Education must be given for at least 10 years followed by compulsory vocational school attendance. Education is also differentiated according to need i.e., if a child is unable to meet the demands of the special program, then an individual program will be set up for him. Pre-school education differs somewhat, in that, it is regarded as a right, but not made compulsory.

Sweden also maintains special programs and facilities for those retarded who suffer severe anti-social behaviour. Part of the rationale for this rests with what the country sees as the positive outcome of preventive measures such as constant supervision, care, employment and organized recreational facilities.

In spite of the high degree of specialized care at the regional level, the main centre for service is provided at the county level; however any plan for service delivery here is subject to approval by the National Board of Health and Welfare and the National Board of Education. In this way the linkages are maintained. This guideline is also effective for private organizations with the expectations that through these means, quality assurance will be built into the program.

### Philosophy

The administration of services at the county level has a significance in terms of philosophy towards the retarded. At best, this administration can be described as following an integrative-normalization service approach. There are no special diagnostic services for the retarded, rather this service is incorporated into the workings of the pediatric and psychiatric clinics which are



responsible for the general health and medical services for all people in the area. The retarded are only serviced by the mentally retarded organization at the time when they require special facilities.

This same principle is being pursued by the regional centres. Present facilities are being re-modelled or re-planned on a community-normalization basis. This accounts for the movement towards single storey, home-like buildings, greater staff to resident ratio, and increased budget allocations to this population. Facilities for the severely and profoundly retarded are also moving in this direction. Custodial institutions are being replaced by modular communities, each community containing no more than thirty residents.<sup>4</sup>

Under the Swedish model a great deal of emphasis is also being placed on day-school education both through special classes in ordinary schools which is consistent with the philosophy of normalization, as well as through the creation of regional vocational schools.

Sweden, probably more than many other countries, is making immense strides in terms of making normalization a reality; however it is a continuous working process as reflected by the fact that there are still about six institutions in the country that house between 400 and 740 residents each. The institutions heterogeneously group the the residents in terms of age. In addition one dayroom will often serve 25-30 persons, which, by Swedish standards, is considered poor service. Some isolation still exists in terms of location of facilities as well as location of schools.

In spite of these needed areas for work, Sweden has adopted a philosophy of service on a national basis. This philosophy is

normalization and every effort is being made to incorporate it into the development and planning of new programs.

### Great Britain

In addition to Swedish and Danish influences, Canada has felt the impact of developments in Britain. Although not as highly articulated in its philosophy as Sweden, Britain's programs have some very progressive and comprehensive features in terms of the education of the retarded.

### Legislation

In Britain, services for the mentally retarded are provided under the mental health services. The Mental Health Act of 1959 emphasized less segregation of the retarded in institutions. As a result, many adult training centres as well as hostels were established in the community.<sup>5</sup>

The cost of providing services for the retarded is shared jointly by the local and national governments. This, at times, becomes a weakness in the system due to the lack of effective co-ordination between the different levels of government.

According to David Norris of the Bournemouth College in Britain, normalization and community integration are regarded as good not only from a philosophical basis but also from an economic basis. This has led Britain into a strong position of support to the ideas of foster care and financial aid to the families of retarded children, as an alternative to institutionalization.

### Administrative Structure

The administration of services for the retarded is based on several interesting principles. One such principle is the split between administrators and clinicians. The British philosophy rests on the assumption that each should do the job that he has expertise in.

A second area of interest is the separation of the management functions of the hostels from those of training centres. This separation is based on the philosophy that it is important for a child to have a separation between home and school. When no separation exists the child is often robbed of his sources of refuge when problems arise in one area.

### Service Provision

Britain's strong belief in the importance of education is reinforced in the training of their teachers for the retarded. This priority culminated in action by the Government when it created the Central Training Council for teachers of the retarded. In addition there is an informal policy of not granting permanent employment status to any employee not possessing certain qualifications in Britain's General Certificate of Education. The quality of staff in terms of their effect on the calibre of programming is regarded as a priority under the British model. This also extends itself to the high staff to client ratio that exists within the training centers. The ratios vary depending upon the level of retardation.

In order to attract high quality people the Adult Training Centres offer attractive packages to interested young people in terms of assistance with their education. This emphasis extends itself to the internal workings of the Centre as represented by the fact that any absences from work as a result of training periods or vacations are compensated for by temporary staff in order to insure that a certain level of service is maintained.

The Training Centre also provides a link between the school and home through the County mental health social work agencies. These agencies operate as a resource to the public education programs.

In Britain, design of facilities follows educational needs. This emphasis is slightly more pronounced in Britain than either Denmark or Sweden where design of facilities follows normalization principles, although both educational needs and normalization principles often coincide, they are labelled differently in these countries. To this end professional designers are employed in Britain to design environments that facilitate and promote learning in retarded children.

These kinds of philosophies are also incorporated into the educating of children. The concept of providing environments where learning based on experimentation can take place is encouraged. To this end, flexibility and diversity are integral parts of the program. Through these means much less importance is placed on the spoken language.

### Philosophy

The present general trend in Britain is one of normalization, in the area of education, and to a lesser extent it is reflected in attempts to integrate residential facilities. This is having less success due to the division and lack of co-ordination between government levels. This creates difficulty in terms of residents involvement in community services as administrative arrangements do not facilitate mutual involvement. The goal that workers in the field of retardation in Britain see for the future is that of greater co-ordination between the levels of government or that all services in this area be administered by one level of government.<sup>6</sup>

### United States

Neither Canada nor the United States have reached the level of service development for the handicapped that exists in the Scandinavian countries. There are pockets of progress that can compare to other models, but as yet both countries lack the more total approach that exists elsewhere.

### History

Prior to 1950 in the United States, little effort was directed to the problem of retardation. Most of the retarded were cared for in institutions; the conditions of which have been so aptly described by such works as Burton Blatt's Christmas in Purgatory.<sup>7</sup>

Until the early 1960's little innovative thinking in terms of alternative provisions or improvement of existing conditions received any impetus from government. However, in 1961 interest was stimulated

by President Kennedy who appointed the President's Panel on Mental Retardation for the purpose of exploring the possibilities of preventing and curing mental retardation. The Panel was also commissioned to study the existing programs with the intention of pointing out the limitations. In essence the Panel was to review and make recommendations with regard to:

1. The personnel necessary to develop and apply new knowledge. The present shortage of personnel is a major problem . . .
2. The major areas of concern that offer the most hope; and the means and techniques, and the private governmental structures necessary to encourage research in these areas.
3. The present programs of treatment, education, and rehabilitation.
4. The relationship between the Federal government, the States, and the private resources in their common efforts to eliminate mental retardation.<sup>8</sup>

This kind of action was a giant step forward in a field in the United States that had hitherto been ignored. Beginning in 1963 funds were allocated by the U.S. Congress to states that were expanding facilities for the retarded.

In 1967 another significant event occurred through the creation of a second President's Committee. The significance rested in the denunciation of the poor state of residential care. The climate created by this report provided the impetus for an awakening look at the theory and principles of normalization as a guideline in the provision of services for the handicapped. The movement towards this model was largely the work of two men--Wolf Wolfensberger and Robert Kugel. Presently this theory and the accompanying premise of

community integration largely forms the basis of many new programs developed in the United States.

### Service Provision

An interesting area of development in the United States provision of services has been in the area of education and training. The Constitution has been used as a basic for court action in a number of cases to ensure the provision of education to retarded citizens. Both the court decisions and federal funding have provided impetus for many states to improve and expand their programs to include such services as day care, home help, transportation and counselling services.

One of the model programs in the United States is that which exists in Nebraska and is termed ENCOR (Eastern Nebraska Community Office of Retardation). This will be looked at in detail as it has served as a model for many individuals engaged in the planning of services in Canada, particularly in Alberta. In addition, one of the main planners of ENCOR, Wolf Wolfensberger, has served as a consultant to the National Institute on Mental Retardation in Toronto and this organization has acted as a resource centre to all provinces.

In 1968, a committee composed of both parents and professionals drafted a plan for a network of community-based programs that was built on the concept of normalization. This same year the Nebraska legislature passed legislation which established six regions in the state that were responsible for service delivery for the mentally retarded. An office at the state level was also created for the purpose of integrating and assisting the regions in their planning.

ENCOR was established on July 1, 1970 by Region VI, which is comprised of five counties.

The purpose of Encor is to provide a continuum of service to meet all the individual needs of the retarded as well as providing alternatives to institutionalization. The philosophy of normalization affects all the decisions that are made concerning programs and service delivery. In addition to this attitude, the philosophy of "continued development" is also an integral part of the planning. Thus, retardates are seen as capable of learning. ENCOR is built on a premise of providing opportunities for learning regardless of intellectual ability and in this way the programming reflects a "next step or goal" approach. Staff training, consumer evaluation and parental involvement are also key elements of the ENCOR program.

The administration of the ENCOR program is very innovative when compared with other existing programs in the United States. General co-ordination and direction for all services is provided by the Central Administrative office. The direction provided is based on several guidelines. These include physical and social community integration, service dispersal according to population and geographical dispersal, specialization and diversification according to client need as well as continuity between programs and services to insure a "total care" concept.

The child development service component of ENCOR can be regarded as comparable to those existing in other countries. The philosophy of the service is individual educational programming based on the needs of the client. General educational objectives include training



in motor development, daily living skills, perceptual and sensory discrimination, social skill and speech and language development.

In terms of residential facilities, ENCOR adheres to the normalization model. Provision for small, family-like residences is made. In addition, family type hostels, room and board situations as well as supervised apartment living is provided to those who can cope with a more independent program. ENCOR provides "developmental homes" for those young children whose needs would best be met in a family situation. This provides an alternative to institutional placement.

Crisis assistance is provided for the family through relief bed space. In addition, a special behavioral unit exists for severely retarded individuals who have behavioral problems. This unit operates on a "behavioral management methodology" and attempts to prepare the resident for more normalized day programs and residential settings.

ENCOR also makes special provisions for the severely mentally and physically handicapped, many of whom were previously regarded as hopeless. A combined residential developmental program exists. The focus is on stimulation, self-help, ambulation, and social and personal awareness and interaction.<sup>9</sup>

In conclusion, ENCOR has been one of the best vehicles in the United States, to date, that has attempted to provide total service to the client on a normalization basis.

Finally, assistance to the retarded gained further impetus in 1975 with the signing of the Education of All Handicapped Children Act by President Ford. This Act established federal commitment for

educational services for all handicapped children. It assures this service by making federal funding contingent upon the establishment of the goal of serving all handicapped persons between 3 and 18 years by September 1, 1978 and those between 3 and 21 years by September 1, 1980. There are also incentive awards built in that focus on early identification, screening, and intervention.

#### Delivery of Service in Canada with Emphasis on Alberta

Primarily the four countries of Denmark, Sweden, Britain and the United States have had an impact upon the evolution of services for the mentally retarded in Canada.

#### Canadian Differences

The present provision of services to the handicapped in Canada has several significant differences from the studied countries. Although a comparison between the countries is difficult due to such factors as culture and different systems of government, it is felt by this writer that a generic view of some of the main areas of differences in terms of service provision to the retarded would be helpful in terms of understanding the Canadian position. Firstly, the Canadian mentally retarded do not enjoy the privilege of either a federal or a provincial law governing the rights of the retarded. There have been laws formulated at the federal level that have provided assistance in financial or training areas. In terms of education and rehabilitation the British North America Act has made education the clear responsibility of the provinces, and by implication, rehabilitation; however in terms of the mentally handicapped little, if any service provision exists within the

educational system for provision of special educational services, particularly for the dependent handicapped.<sup>10</sup>

In terms of financial assistance to the retarded the federal government, through the Canada Assistance Act (1966) has engaged with the provinces on a cost sharing basis. Under this arrangement the federal government pays 50 per cent of the costs of social assistance for the adult mentally handicapped as well as 50 per cent of the costs of those who are wards.

Another development in terms of financial assistance to the retarded occurred in 1961 with the passage of the Vocational Rehabilitation of Disabled Persons Act (VRDP). Part of the purpose of this Act was to make federal funds available in the areas of training, education, and employment to that population that was physically or mentally impaired to the point where they were "incapable" of pursuing regularly or substantially gainful employment,<sup>11</sup> A second purpose of this Act was to make research funds available that would be directed toward increasing the success of vocational placements.

VRDP is administered by the Department of Health and Welfare. It enables the federal government to enter into agreements with the province for a maximum of six years. Unfortunately extensive use of these funds have not been utilized by the provinces. The traditional difficulties between the federal and provincial governments over cost-sharing and conditional grants could be part of the reason for this.

There has been a movement in Canada to repeal the Vocational Rehabilitation of Disabled Persons Act through Bill C-57 (The Social Services Act). This Act has been significant through its attempt to make federal legislation in the area of general social service provision. It has attempted to separate the need for financial assistance from the need for other general social services. If passed Bill C-57 would amend the Canada Assistance Plan, repeal the Vocational Rehabilitation of Disabled Persons Act as well as extend the federal government's cost-sharing role into developmental social service areas and thus broaden service provision to the handicapped.

A second major area of difference in Canadian service provision is the lack of a clear planning philosophy in terms of the retarded. Although much of the present literature stresses the normalization model, little exists in the way of a national philosophy. The difficulty associated with adopting a national philosophy seems to be compounded by Canada's system of federalist government. The closest Canadians come in terms of national linkages is through private associations such as the Canadian Association for the Mentally Retarded (CAMR). This Association was formed in 1958 and is presently a federation of 350 provincial branches with a membership of 35,000.

There are three divisions of CAMR. These are the Association Support and Development Division whose purpose is to provide advice to member units. The National Institute on Mental Retardation (NIMR) which is largely directed towards research, training and program development in Canada and the Institute National Canadien-Français

Pour La Deficience Mentale (INCF) which is the French speaking branch of the association.

NIMR carries a fairly high profile in terms of assistance to the retarded. It assumed independent status in 1969 and presently co-ordinates services throughout Canada. One of the main functions of NIMR is the provision of a library service. This has extensive literature as well as audio-visual material on the retarded and it serves as a national reference and resource centre. A secondary role played by NIMR is that of workshop planner, program, and personnel consultant.

#### Service Provision

An interesting development in the field in terms of national concern for an adequate service occurred in 1964 at the "Conference on Mental Retardation" which was jointly sponsored by the federal and provincial governments. This conference stemmed from concern over what was interpreted as a fragmented and inadequate service. The result of the conference was the planning of a series of demonstration and research projects across Canada with the hope that this would expand the professional and technical base of service delivery as well as develop improved methods in terms of identification of needs. In 1967 fourteen "Centennial Projects" were planned. Funding came from all levels of government and amounted to fifteen million dollars. Alberta was the site of three projects. Edmonton was the centre for two of them--The Western Industrial Research and Training Centre (WIRTC) and the Centre for the Study of Mental Retardation. Calgary became the site for the Vocational Rehabilitation and Research Institute.

The purpose of WIRTC was to undergo research into possible occupational capabilities for the retarded as well as exploring the possibilities of their acquiring sufficient skills to become employed. Enrollment was 175-225 trainees. An objective of WIRTC was to reach clients in small communities, train them and return them to their own community. This was never realized.<sup>10</sup>

The Calgary centre--the Vocational Rehabilitation and Research Institute (VRRI) has strongly emphasized research in terms of assessment, training and social recreation. It is linked to the University of Calgary and it serves approximately 300 trainees in vocations such as gas pump attendants, kitchen works, workshop employees and bottle depot attendants.

The last project--the Centre for the Study of Mental Retardation--is located at the University of Alberta. It's been developed in conjunction with the University and focuses on the effects and management of mental handicaps.

In addition to these projects, CAMR also became involved in such studies as the Celdic Report--"One Million Children." This report was not only concerned with the mentally retarded but more broadly with any disadvantaged child.

The advent of the 1970's brought new impetus to CAMR in terms of the development of comprehensive community services for the handicapped. This encompasses CAMR's primary focus at this time. It was not possible to simultaneously implement programs throughout the country therefore a number of Experimental and Demonstration (E & D) projects were undertaken. One such project was begun in

Lethbridge in 1972. At this same time the provincial Division of Services for the Handicapped was created. This has greatly affected service delivery in Alberta. The primary purpose of the Division is to develop, encourage and fund services for all handicapped in the province. This broad mandate was partly in keeping with the Progressive Conservatives' 1971 election platform at which time it was pledged that greater care for both the mentally and physically handicapped would be undertaken. The Division is also charged with the responsibility for all institutions caring for the handicapped.

Another major development in terms of service delivery was an amendment to the Child Welfare Act in May, 1974. This amendment allowed parents with handicapped children to apply for financial assistance to cover those costs that they would not normally incur if the child was not handicapped. The arrangements for assistance are on a cost-sharing basis where parents are financially able, or the government will assume total cost if the situation necessitates it. This provision provides incentive to parents to maintain their children in the home or at least to maintain contact and an interest in their child.

Another development occurred in Alberta, in Edmonton, in 1974 and was directed to the improvement of educational opportunities for the handicapped. A group known as Gateway began to pressure for better education.<sup>11</sup> This pressure resulted in classrooms for mobile toilet trained children. A second major development occurred in Edmonton with the acceptance by the provincial government of a development plan known as the "Cormack Plan." This proposal was

sponsored by the Division of Services for the Handicapped. It consisted of engaging a professional planning body and utilizing the professional in the field to develop future centres for both residential and day care programming. It is projected that by 1980 five community based resource centres, each having an attached residence and group home will be built. It is expected that the centres will accommodate twenty individuals and will offer day training to ten more who reside in their own homes. The residences would accommodate the dependent handicapped who do not require constant medical supervision. Those who require medical supervision are being accommodated in a medically oriented facility--the Cormack Centre.

The Cormack Plan was developed on the principles of normalization and community integration. It's overall goal was to enable the handicapped to live in their own communities. The planners of this network of services used information from both the Scandanavian and Nebraskan experiences.

Another major development in Alberta was the committment by the provincial government of funds to hire technical planning consultants to provide planning expertise to the "Calgary Community Planning Organization" for the development of a feasibility study to implement the recommendations of the "Baker Plan" (now known as the Calgary Plan). The Calgary Plan was the result of co-operative efforts by government, community agencies, and volunteers in their effort to develop a network of services for handicapped people in the Calgary area.



The Baker planning process began in February, 1975 with the establishment of the Baker Planning Committee by the Regional Co-ordinator of Services for the Handicapped. This was to serve as an advisory committee with representation from parents, agencies, city and provincial governments, and expert planners. The mandate was to propose an alternative to the Baker Centre, which is the residential facility for mentally handicapped children and adults and to establish linkages with existing programs in Calgary. The community was involved in creating five task forces (total of 80 members) whose purpose was to make recommendations on ways to implement the Baker mandate for specific age groups.

In order to acquire a complete understanding of the needs of the population a census was done in 1975. This census identified individuals based on need rather than degree of retardation.<sup>14</sup>

The Calgary Plan is presently in Phase II of its operation i.e., through the assistance of 13 community committees it is presently developing an implementation proposal to operationalize the recommendations. The present objective of the community committees is to complete a feasibility study which will delineate services, resources needed, and estimated costs over a five year period. Each committee has as its task the above objective for different areas of service and partially for different segments of the handicapped population.

The situation in Canada and specifically in Alberta appears to be moving in the direction of community integration. Canada, itself, lacks the kind of overall guidelines and legislation that

exists in some of the other countries that were studied; however movement in similar directions is reflected in the planning of today.

### Summary

In this chapter, the writer has described the services for the handicapped that exist in the countries of Denmark, Sweden, Great Britain and the United States. There was some discussion of the Canadian service system, particularly the Alberta situation. In addition, there were some generalizations in terms of broad differences between Canada and the other studied countries.

In relation to the mild, moderate and severely retarded individuals the major emphasis appears to be toward training, development, and the creation of normalizing environments. There also appears to be an emphasis towards the goals of development and normalization in accordance with the assessed needs of the dependent handicapped (severe to profound). The fact that the dependent handicapped are given the least single attention in the literature appears congruent with the present uncertainty in understanding the capabilities of this group, and that this uncertainty will be reflected to some degree in the community planning recommendations (Chapter IV) as well as the parental survey response, (Chapter VI).

## NOTES TO CHAPTER III

1. The Board of Directors is composed of eight members. These are appointed positions. Representatives are from the National Health Service, Ministry of Education, parent association and five interested community people.
2. The Central Tribunal is set up by the Minister of Social Affairs and is composed of a chairman, a social worker and a psychiatrist.
3. The organizational structure of the County Council has several interesting features. It consists of 98 members, headed by the Board of Administration under which there are six sub-committees. One of these is called the Committee for Educational and Social Services, which, in turn, has under it the Board for the Services for the Mentally Retarded.  
The Board is composed of seven appointed directors and meets monthly. Its daily activities are handled by a staff of seven, including a "chief of care" and an assistant (both social workers), a psychiatric social worker, and an occupational therapist. Attached to the central office staff are a school principal and a consultant child psychiatrist.
4. Each residential community is divided in half by the staff office, bathroom units and the kitchen. Each half is further divided by the resident entrances into sections for seven or eight persons each. The four sections share a combined corridor--dayroom, and there is one dayroom and dining room for every two sections. There are bedrooms for one, two or four residents, and each resident keeps his clothes in closets along the corridor. A separate building houses the administration offices, assembly hall and a sheltered workshop.
5. A junior training centre serves children who are mostly in the moderately to severely retarded range. In American terms, it is equivalent to a combination day care centre and school for trainable children. A senior or adult training centre is equivalent to a sheltered workshop and rehabilitation service, mostly for the moderately to severely retarded.
6. General particulars on Britain's programs have been provided by David Norris in his article "An Urban-Rural Area in Britain" in, Changing Patterns in Residential Service for the Mentally Retarded; ed. Kugal and Wolfensberger, Washington: President's Committee on Mental Retardation, 1969.

7. Blatt was stimulated in his research on institutional conditions by comments made by Senator Robert Kennedy in 1965 after Kennedy's inspection of several institutions. Kennedy's comments both shocked and infuriated the American people. The Kennedys have maintained an interest in this area. They have a retarded sister.
8. The President's Panel on Mental Retardation, "Proposed Program for National Action to Combat Mental Retardation," Washington, D. C.: The President's Panel, 1962, p. 201.
9. State Office of Mental Retardation, Eastern Nebraska Community Office of Retardation, Omaha, Nebraska: Encor, n.d., unpaginated.
10. The legislation has recently been tested both by a parent in Edmonton and by the Director of the Providence Child Development Centre in Calgary who have registered handicapped children in the regular school system.
11. Canada, Vocational Rehabilitation of Disabled Persons Act, 9-10 Elizabeth II, 1961, Chapter V-7, Article 2.
12. Funding for this program was withdrawn on September 1, 1976. It was previously supported through Services for the Handicapped. No research was carried out.
13. Gateway resulted from a split in the CAMR membership in 1974. The new group adopted the name Gateway.
14. Division of Services for the Handicapped, Resources for Handicapped People - A Calgary Community Plan, Calgary, Alberta: The Division, April, 1977.

## CHAPTER IV

### CASE STUDY - THE CALGARY PLAN

In this chapter an ideal service and facility, as outlined by a community committee under the Calgary Plan, will be discussed. The Calgary Plan is defined as the process involved in planning a comprehensive network of services for the handicapped in the Calgary region. In 1972, a Division of Services for the Handicapped was established within the Alberta Department of Social Services and Community Health. The division was given responsibility for the development of regional systems of community services for the mentally retarded and physically handicapped. Before the division was formed, most of the services for the retarded in Alberta were contained in a 2400 bed institution in central Alberta (Red Deer).

The assignment of regional co-ordinators to six regions within the province followed. Concurrent with the appointment of the regional co-ordinators came the Provincial Government's policy announcement reducing the size of the provincial institutions. This was to coincide with regional service development and it was hoped that the outcome of these efforts would be the return of institutional residents to their region of origin. Approximately one million dollars in per diem grants were made available to agencies wishing to develop local residential services, vocational training, and specialized child development services for the mentally retarded.

In 1972 the majority of the severely/profoundly handicapped in Calgary resided in the Baker Memorial Sanitorium. This building was originally established in 1919 to treat veterans and civilians suffering from tuberculosis but in the early 1960's, with the decline of this disease, part of the facility was remodelled to house retarded infants and pre-schoolers who required on-going health maintenance. By 1963, the population of the sanitorium had grown to 117.

In 1973 greater responsibility for the handicapped at the Baker Sanitorium was turned over to the Division of Services for the Handicapped. At the same time the Department of Public Works completed a site review of the Baker facility and the building was declared unsafe. The need for alternate facilities became imperative. In the interim, part of the building was remodelled to serve as temporary accommodation.

In February, 1975 the Baker Planning Committee was established by the Calgary Regional Co-ordinator of Services for the Handicapped. This body was to serve as an advisory committee representing parent groups, agencies, city and provincial governments, and interested individuals. It was also given a mandate to propose an alternative to the Baker Centre as well as to establish linkages with existing programs within the region.

Community involvement was established through the creation of five separate task forces (Phase I). These task forces were to recommend ways of implementing the Baker Plan mandate for certain age groups. The reports of the task forces resulted in the establishment of an Interface Committee charged with the responsibility

of integrating and adjusting the reports for the purpose of achieving a comprehensive network of services. This resulted in what has been termed the "Feasibility Study" (Phase II) of the Calgary Plan. Phase II is to design ideal programs and provide cost estimates for a comprehensive network of service. To carry out this task thirteen community committees, each in charge of different service project areas, were established. Because of the magnitude of Phase II this study will focus on the work of one community committee, the Residential Special Care for Children and Adults Committee and special attention will be given to the population of severely and profoundly retarded children and adults with extended health care needs.

The Calgary Plan, of which the committee is a part is unique in its use of the community for defining and costing a comprehensive service system particularly a system that is being designed to bridge many different jurisdictional areas and professional disciplines.<sup>1</sup>

Definite planning principles and goals are being utilized in this plan. In terms of the planning, collective leadership is provided by the Calgary community; whereas co-ordination leadership is given by the Division of Services for the Handicapped. Technical planning assistance is also provided by Alberta Housing and Public Works through its consultants, Status Project Planners. The participants, functions, and reporting relationships are shown on the organizational chart, (See Appendix A). The chart also provides a visual representation in terms of how the Special Care

Residential for Children and Adults Committee fits into the total scheme.

The broad goals of the Calgary Plan are as follows:

1. To develop an implementation proposal (Feasibility Study) to operationalize the Baker Plan.
2. To limit government control of the planning process.
3. To optimize the Calgary community participation in providing for its handicapped people, utilizing government support.

These goals will lead to the completion of a feasibility study which will identify services, resources needed, and estimated costs projected over a five year period starting January 1, 1979.<sup>2</sup>

#### SPECIAL CARE RESIDENTIAL FOR CHILDREN & ADULTS COMMITTEE

##### Mandate:

From the beginning of its operation, a body must be aware of the expectations that are being placed upon it. Having received its mandate, an organization knows:

- (i) that a collective decision has been made to recognize a problem or need as deserving of interventive action;
- (ii) that authority has been granted to the organization to address the identified problem and;
- (iii) that resources have been provided whereby the problem can be addressed.<sup>3</sup>

When a recognized social collectivity such as the government declares a social need to be worthy of intervention, then some credibility accrues to the agency that is assigned the authority to intervene. A concise statement of authority and scope of responsibility provides a sense of purpose and clarification for



for what and to whom the organization is accountable. Without a statement of specific authority, a body may temporarily enjoy a sense of autonomy to plan services as they wish.

A mandate implies the allocation of resources to fulfil the stated responsibilities. The adequacy of the resources will significantly influence the extent and intensity of action that is taken. Ideally, the resources will be allocated in accordance with the scope of the body's responsibility.

Using this definition of a mandate, the committee, under the Calgary Plan experienced difficulty. The Government granted authority for the Calgary Plan to the Division of Services for the Handicapped and this, in turn, was delegated to the community committees. A problem arose because of the lack of resources. There was no budget allocated to the committees which significantly effected the work they could do. In addition, the entire Plan received only \$108,000 for the purpose of hiring technical planning consultants and the "understanding" that the government would consider the outcome of the Calgary Plan. As a result most of the work done was voluntary. This created many problems in terms of time commitments and availability of expertise.

The concise statements of authority and scope of responsibility as defined in the mandate of the committee for Category III Level C clients was as follows:

- (i) The design and costing out of a unit or units to accommodate approximately fifty profoundly and multiple handicapped children in need of nursing care and medical supervision plus extended residential care.

- (ii) The design and costing out of a unit or units to accommodate fifty profoundly and multiple handicapped adults who require nursing care and medical supervision plus extended residential care.
- (iii) Design and cost out the day<sup>4</sup> program requirements for the above groups.

### Goals and Objectives

Goals and objectives usually reflect value orientations.

Hasenfield and English comment that "in human service organizations, the definition of goals are primarily commitments to certain values, norms, and ideologies."<sup>5</sup>

The Committee adopted as its broad goals, those goals of the larger system, mainly:

- (i) to develop and cost out a proposal that would represent an ideal service system for the populations.
- (ii) to limit government control of the planning process
- (iii) to maximize community participation

In addition, The Committee added a fourth goal:

- (iv) to build an ideal system based on client need, i.e., the needs of handicapped persons as opposed to the needs of the organizations providing the service.

Objectives are closely related to both the mandates and goals. They must embody the general goals as well as specifying particular desired outcomes. According to S. G. Deeds: "Objectives are statements of intent; they communicate the direction and shape of programs."<sup>6</sup> Objectives must be stated in terms that are realizable and measurable and they generally form the basis on which subsequent evaluations are made.

In attempting to define its objectives, the committee identified the problems of the dependent handicapped as being both their

dependency and vulnerability in terms of their health. As a result, they used these problems as guidelines in developing objectives. They also set a time limit of June 30, 1978 as the date when the residential program design would be completed and in report form.

Upon reviewing the minutes of the committee the following objectives were synthesized:

1. To produce a residential program design that would provide the opportunity for this population to progress to whatever degree possible regardless of age or severity of disability.
2. To recommend an approach that was developmental, moving away from custodial care which was interpreted as being non-normative.
3. To provide regionalized resources.
4. To provide family support functions.
5. To employ the use of specialty services (eg. medical, recreational), rather than generic resources.

#### Task Achievement

The major achievements of the committee were in the areas of identifying the facility and programs required based on an assessment of client needs, and the identification of current trends in the population that had implications for planning.

In the past the trend had been for many parents to institutionalize their dependent handicapped child. Accommodation at home had been atypical partly due to the lack of supportive community resources. At present developmental day programs are providing a form of parental relief. As a result, pressures are reduced on families and early institutionalization is becoming less common. The present trend, however is creating an increased demand for relief bed space. In relation to the present trend, the committee forecasted the lack

of trained manpower to service the dependent handicapped in a developmental manner as a major limitation for the implementation of their recommended ideal service system.

Client needs were established by the committee as a result of consultation with professionals and parents associated with this particular population. Local exposure to existing services provided the input from the professional sector. Parental input was limited to those parents who were members of the committee.

The list of needs assessed by the committee is as follows:

A. Physiological Needs:

1. To be fed
  - proper nutrition
  - variety
  - flexibility of feeding schedule
2. To eliminate
  - bowel movement
  - diet
  - exercise and movement
3. To be cleaned
4. To sleep (uninterrupted)
5. To maintain body heat - clothed
6. To have air
7. To be free from pain and discomfort
  - changed diapers
  - medication
  - back rubbed
  - movement (turned, rotated)
  - range of motion exercises
  - room temperature/air
8. To be cared for in terms of health - physical, mental, and dental
  - maintenance
  - prevention

B. Sensory Stimulation:

1. To experience variety in diet
2. To experience environmental stimulation and diversity
  - lighting
  - fresh air
  - smell, color, pattern, sound
3. To experience tactile (touch); stimulation (air)

C. Esteem and Belonging, Love:

1. To be involved in interpersonal contact
  - staff
  - peer
  - family
2. To be challenged and to be provided with opportunity
  - gross motor development
  - fine motor development
  - range of motion exercises
  - recreational (tactile stimulation)
3. To be cared for
  - dignity
  - respect (of significant others)

D. Safety:

1. To have supervision (bedchecks, etc.)
2. To have provision for environmental safety
  - beds
  - equipment
  - accessibility to outdoors (evacuation)

E. Continuity of Care:

1. To have the stability and assurance of having needs met
2. To have care that is co-ordinated and integrated
3. To have care that is administered and staffed conscientiously

F. Continual Quality of Having Needs Met:

1. To have staff issues regarded as important
  - personal qualities
  - educational qualities
  - salaries and benefits

- training
- provision of challenge, movement and initiative
- lines of communication
- relief

G. Greater Understanding:

1. To pursue greater understanding of the handicapped
  - research - liason with other institutions and universities
  - community education

The staffing module and costing frameworks evolved directly from the description of need according to the following flow:

NEED - SERVICE - SKILL - DISCIPLINE --> AMOUNT-----> COST  
(PROGRAM)

The need determined the service required which, in turn, dictated who was to provide the service and in what quantity. Staff costs were then computed based on the amount required to provide the ideal service. A detailed breakdown of the staffing model is included in Appendix B.

In essence, the committee was utilizing a deductive method for arriving at their ideal system. Looking at the ideal service objectives as being the purpose of their work, the committee attempted to define the best ways to achieve them. Participation was seen as an important component and an attempt was made to involve all levels of people who were part of the system.

Two main areas of difficulty encountered by the committee were those of the health status of the population as well as the size of the structure for special care residential placements. Conflicting viewpoints resulted in a compromise decision in terms of facility size

and the emphasis on health requirements. On one hand normalization principles stressed small community units with a low profile. This perspective was enhanced by Edmonton's experience with the dependent handicapped. Personnel from the Division of Services for the Handicapped in Edmonton found that their 92 bed institution--The Eric Cormack Centre which accommodated profoundly handicapped children and adults was demonstrating increased health stability by residents who had been deemed medically dependent. Some of these residents had been engaged in programs of daily activation. For further validation of this, Services for the Handicapped in Edmonton sampled 100 residents to assess their capacity to be accommodated in a setting without on-going nursing supervision. The 100 were in institutions that were orientated towards achieving health stabilization of its residents. The results indicated that 50 per cent were stable and capable of functioning without risk in a community setting.<sup>7</sup> In addition, this study was reinforced by several parents who were indicating that their dependent handicapped children were not sick in spite of having complex health conditions.

The other extreme, i.e., the necessity of building on the basis of the health concerns was largely vocalized by the professionals in the field, i.e., doctors, nurses and day care supervisors. This group stressed the importance of nursing care and the health vulnerability of even the stabilized residents. They also felt that to provide adequate health service that the population needed to be grouped. Respiratory problems were cited as being very prominent, along with the difficulty of servicing this need in a facility such as a group home.

The outcome of the committee's work was the recommendation of a facility that was to be built on a modular basis, with a strong nursing component. It was to consist of two arms, each arm containing 50 residents in total, with living units set up on an 8-10 bed modular basis. The two fifty bed arms were to be separate in terms of client needs, thus separation based on age was not a criteria. One arm was to serve the more developmental population with the other unit providing on-going health maintenance to the chronic and deteriorating population on a long-term basis. Provision for streaming between the units as well as into the community, depending on changing health conditions was seen as essential. The common facilities such as a pool, hydrotherapy areas, and day programs areas were located between each of the 50 bed communities.

The facility was to contain two special units each with four beds. One unit would be used for those with chronic respiratory problems where oxygen would be available. The second would be an isolation unit. Provision for relief beds was to be included. In addition, staff would be shared between the two fifty bed communities.

Location of the facility was to be within the community and not on the periphery and preferably near a hospital in order to facilitate the use of existing x-ray and laboratory services, as well as acute care transfer, teaching and specialist access.

It was recommended that the "Day Program" be incorporated into the running of the facility and that it be operated on an 8 hour - 5 day a week basis. The environment where the day program was, was to be abundant in stimulation and enrichment; for example, components such as swimming pools, mats and music were to be included. The location



of the day program was to be on site but separate from the residential area. The program was to be run on a half day basis, i.e., 25 residents out of the community would be in the program in the morning and the remaining 25 in the afternoon, i.e., half of the population in each module of 10. As a result, there would be two programs operating concurrently. It was also recommended that the use of volunteers be incorporated wherever practical and possible.

The committee also made recommendations concerning possible administrative models. Because of the committee's uncertainty in terms of the optimal administrative structure, the following options were suggested:

It was unanimously agreed that the Residential and Day Program components for this client group have the same administration; this being seen as essential for program co-ordination and continuity of care. To administer this facility The Committee recommends the following options:

(a) Option #1

That the facility be established as a Provincial Crown Agency and administered by a Board of Directors appointed in a manner that would satisfy both the requirements of the Crown Agencies Act and the needs of the local community. In other words, the Committee desires strong local and consumer input into the choosing of the Board of Directors.

This is a profoundly dependent handicapped group and the people of the Province must ultimately be responsible for their care. In addition, there is a strong requirement for organizational stability while, at the same time retaining a high degree of community accountability.

This option is favored over the present system of administration directly through the Division of Services for the Handicapped.

(b) Option #2

To administer the facility through a private society established within the community of Calgary and incorporated under the Societies Act of the Province. While in some ways this option is favored by the Committee in that it is expressive of the community being, in a private manner, strongly accountable for the needs of this client group it is listed as the second option because it does not incorporate the guarantees of continuity of care, etc. that the first option envisages.

Evaluation of Recommendations

The recommendations of the committee generally met the objectives that it set for itself. The opportunity for development and progress was incorporated into the day program. In addition, an emphasis was placed on locating the facility in the community for easy accessibility by families and staff. This, along with the provision of relief bed space, offered families an extra dimension of support. The use of specialty services was reinforced in the staffing model. The compromise the committee reached in terms of the dissension over the significance of the health needs as well as the size of facility was evident in terms of the recommendations for "streaming" residents according to changing health conditions as well as attempting to deinstitutionalize an institution through modularizing. In essence, the committee adopted a contingency approach in regard to the health status through the provision of streaming.

The kind of service and facility recommended is a reflection of the committee's attitude towards this population. There seems to be some overlap in terms of the perception of the retarded as a "sick" or as a "developing" person. (Being "sick" implicates the constant

need of professional health services which is distinguished from being "at risk" due to a complex health condition). This ambivalence between the "sick" or "developing" person is perhaps understandable due to the individual differences that exist between members of this group. The recommendations do reflect this ambivalence although there is an attempt to make provisions for individual differences through contingency planning.

In reference to goal achievement, it seems significant to evaluate how strongly the committee achieved its goal of basing the system on client need. In many ways normalization can be regarded as a philosophy based on client need rather than organizational convenience.

Certain normalization principles are incorporated into the committee's recommendations, although there is not a complete commitment to normalization thinking. One of the major concepts of normalization is integration. Physical integration is achieved by such means as location and the committee recommended that the facility be located within, rather than on the periphery of a community where access and exposure to the public is increased. The social integration concept of normalization could run into difficulty in terms of "labelling." Location of a residence near an acute care hospital could contribute to an overload of what could be seen as "deviants" within one part of a community and this could in turn affect the degree of integration that takes place. This would depend, however, on how the structures were set up. In addition, the decision not to recommend the use of generic services because of what was

interpreted as the general lack of expertise of community people and the obvious advantage of specialists could result in a continuation of a lack of understanding about this population which in turn, could have an effect upon integration. The strong nursing component built into the program could have an effect upon how this population is perceived by the public. This kind of image association is proposed as a concern by normalization thinkers.

Although the facility that is recommended is an institution by the nature of its size, it is recommended that it be community based rather than an isolated entity and that the use of volunteers be encouraged. There again, there are efforts at achieving integration within the confines of what are interpreted as essential medical needs of the population. In addition, attention is paid to the appropriateness of settings through the provision of "streaming" as well as the separation of life functions in time and place between the day program and residential care. These concepts are again consistent with normalization thinking; as is the attention paid to the ideas of "individualization" and "interaction" in terms of residents and staff, i.e., do staff support individual expression of client needs and is there a suitable amount of time for residents and staff to form healthy, continuous relationships. To the extent possible, safeguards towards these ends have been built into the recommendations through the staff-to-resident ratios.

The committee's second goal, that of limiting government control of the planning process, seemed reasonably achieved. The committee exercised its own judgment in terms of the sources it contacted in

developing its recommendations. Vested interests of professional members were offset by the inclusion of a wide variety of such people who provided their own checks and balances; thus various political interests seemed to be evened out.

In reference to the third goal--that of maximizing community participation--some questions exist in the mind of the writer in terms of how well this was achieved. Although the community committees had representatives of interested persons, both professional and lay, it did appear that the lay people, such as the parents, were often overwhelmed by the professional sector and that the ideas of this group were often not articulated to the same extent as those of the professionals. There is no doubt, however, that the professional community was significantly contacted in terms of the need assessment carried out by the committee.

The committee's general goal was to create a system based on client rather than organizational need. The significance of an ideological perspective towards a population and how this perspective affects the conception of need and resultant human management model is reflected in the work of the committee. The question of whether a population can be both medically dependent and yet capable of development was constantly addressed by the committee. To reinforce the words of Dartington and Miller "the handicapped . . . has to be classified as either less than a whole person or else 'really normal'".<sup>10</sup> This desire to slot the dependent handicapped as either "sick" or "developmental" led the committee into much debate on conflicting merits of the health and medical approach with its ties

, to institutionalization and organizational need and the normalization approach with its ties to client need priority and led, in the end, to the adoption of a contingency approach, which carried some implications towards organizational need priorities. As Kinkaïd points out the:

Contingency approaches recognize that . . . uncertainties can produce serious penalties. To avoid the penalty of misjudging whether action A will result in B or C, contingency plans are developed so that the manager is prepared for either eventuality, B or C. Contingency approaches are based on predictive scripts of what could occur.<sup>11</sup>

The provision for streaming based on changing client situations can be interpreted both as a contingency plan, as well as compromise between alternate viewpoints, which is not atypical in a planning committee which operates on unanimity in decision-making. This unanimity can spell inferiority or excellence in decision-making. A look at the results of the survey of the parents, who can really be looked at as the users, i.e., clients of the service, and their perceptions of need should provide a framework to evaluate the recommendations of the committee. It should help in evaluating whether community participation was maximized and to what extent the service system was responsive to client rather than organizational needs.

### Summary

In this chapter the Calgary Plan as a model of a community planning process has been discussed. The writer has looked specifically at one committee in this plan and has outlined the work done by this committee on a community planning basis. The chapter

has concluded with some evaluation of the work of the committee in terms of its goals and objective achievement and as a result of the questions raised provided an introduction to the research questions addressed in the next chapter.

## NOTES TO CHAPTER IV

1. This is being regarded by the Services for the Handicapped as a pilot project that, if successful, has the possibility of being generalized to other services and communities with different client populations.
2. Status Project Planners, Calgary Community Planning Organization Guidelines, Edmonton, Alberta: Status Project Planners, 1977.
3. J. C. Ryant, "Personal Social Services in a Period of Economic Restraint," The Social Worker, 1976, 44:4, pp. 95-100.
4. Special Care Residential Committee, First Interim Report - Calgary Plan - Resources for Handicapped People - Special Care Residential Committee, Calgary, Alberta: The Committee, February, 1978, 1.
5. Y. Hasenfield and R. English, Human Services Organizations, Ann Arbor: University of Michigan Press, 1974.
6. S. G. Deeds, Writing Behavioral Objectives for Health Education - Student Handbook, n.n.: John Hopkins School of Hygiene and Public Health - Health Education Division, 1975.
7. Perry Kinkaid, "Residential Options for the Severely Handicapped," Edmonton, Alberta: Division of Services for the Handicapped, September, 1977.
8. This outline of needs was synthesized from data collected by this researcher and another committee member - Maryanne Murphy.
9. Special Care Residential Committee Calgary Plan - Resources for Handicapped People - Special Care Residential Committee - Summary and Conclusions, Calgary, Alberta: The Committee, June 15, 1978, pp.8-9.
10. Tim Dartington and Eric Miller, "A Brave Face for the Handicapped," Social Work Today, 1977, 9:11, p. 9.
11. Perry Kinkaid, "Guidelines to Planning and Implementation," A Report to the Division of Services for the Handicapped, Edmonton, Alberta, n.d., mimeographed.



## CHAPTER V

### INTRODUCTION TO THE SURVEY

#### Statement of Research Problems

Services for the mentally and physically handicapped have recently received wider public attention in Alberta, since the 1971 provincial election. As part of its election platform, the Progressive Conservative party pledged itself to provide better care for the mentally and physically handicapped. Since the election there have been definite steps in this direction. The Edmonton Division of Services for the Handicapped has applied for and received complete approval from the Cabinet for the implementation of the first phase of the Cormack Plan. This plan encompasses the planning and provision of services and facilities for the dependent handicapped in the Edmonton region. It is estimated that five million dollars will be spent in this effort by 1983, specifically for the development of five community based resource centres which are largely being designed to meet the needs of the population of the handicapped that are classified as Level III and IV.

In addition, the Alberta Government has given the Division of Services for the Handicapped--Calgary branch, \$108,000, plus the utilization of staff time for the purpose of hiring planners to assist in the study and development of a comprehensive network of services for the handicapped population in the Calgary region. This has been termed the "Calgary Plan" and has been dealt with in the

preceding chapter. This plan is now in phase II of its operation. By these efforts it appears that the provincial government is serious in its intention to increase the level of care of the handicapped in Alberta.

It appears significant, at this time, to look at the community planning process and some of the recommendations of the Calgary Plan. These recommendations will reflect the community's conception of the needs of the retarded. This will be indicative of their ideology. It is generally reflected in the literature that the ideology held by the planners has definite implications for the human management model that evolves in the care and treatment of this group.<sup>1</sup>

It is also felt that it is important to know how the parents perceive the programming and residential needs of their children and if there is any difference in the ideological approaches between the parents and the community as represented by the committee of the Calgary Plan as this would have implications in the utilization of any service.

This study is not only concerned with what parents see as an ideal service for their children, but is also geared to exploring how they feel about integrating the services into the community under certain "normalization" guidelines.<sup>2</sup>

The final analysis of this study will attempt to outline if there is any difference between the community's conception of need and the consumer's, (in this case the parents of Level C, Category III of handicapped children) conception of need. Although there was parent representation on the community committees there was no attempt to

determine the needs of the larger parent community. The parent representation on the committees were, in fact, representatives from different parent organizations.

The difference between the expert's definition of need and the consumers definition of need is referred to by such writers as Jonathan Bradshaw<sup>3</sup> and Anthony Forder.<sup>4</sup> Both these writers deal with the concept of need as well as the value judgments associated with it. They also draw linkages between need and the development of goals in service programming. The subjectiveness of one's definition is also stressed by these writers and it is proposed that this definition is based on the defined interpretation of a minimal standard.

Both Forder and Bradshaw define needs in terms of four categories: normative needs, felt needs, expressed needs, and comparative needs.

#### Normative Needs

Normative needs are those that are defined by professionals or experts. These are defined against some agreed standard which is established by a larger system, often society. Bradshaw stresses that normative needs are not absolute in the sense that they may conflict with needs established by other definitions or there may be conflicting standards between experts. Bradshaw further stresses that the normative definition of needs may be different according to the value orientation of the expert on such matters as needed resources and availability of skills. He also stresses the changing nature of normative standards as a result of knowledge development and value changes.

### Felt Needs

Felt needs are those needs which are equated with want. It is a person's individual feeling of a difference between what is and what ought to be. Bradshaw interprets felt need as an inadequate measure of real need due to the limitations imposed by an individual's perceptions. Forder stresses that "felt need is a necessary condition of self-referral on which services are based."<sup>5</sup>

### Expressed Need

Bradshaw defines expressed need as being "felt need that turns into action. Under the definition, total need is defined as those people who demand a service. One does not demand a service unless one feels a need but, on the other hand, it is common for felt need not to be expressed by demand,"<sup>6</sup>

Services created only for expressed demand run the risk of reflecting only those persons who are in a position to be heard. The Calgary Plan established committees which were representative of those parts of the community which had both professional knowledge and interest in the subject of handicapped services. The consumer, i.e., the population of the parents of handicapped children was the one part of the community that was not requested to express their needs as a total group. However, there was parent representation on the committees. These parents in turn, were representatives from parent organizations and they appeared to carry a higher profile in terms of involvement in such activities than many other parents, they also ran the risk of being overpowered by the professional representation.

### Comparative Need

Comparative need has been interpreted by both Forder and Bradshaw as being an extension of normative need. It is considered to be those needs of a group who are not in receipt of service but who have similar characteristics to those receiving service. In reference to this study it could be those individuals who are as handicapped as the population at the Baker Sanatorium but who are still residing at home. Those not in receipt of the residential service are considered in need. It is important for planners to be aware that most of this population will probably, at some point, require residential service.

A major difficulty in utilizing needs as an indicator for service rests with the fact that there is no definitive meaning for the term need. As a result, Bradshaw proposes that services can be developed by mixing the needs. By not mixing the needs the service becomes responsive to only one area. For example, if the service only reflects the felt need of the consumer, it may politically be inadequate by not taking into account such factors as resources and alternatives. However, if a consumer's need is not acknowledged a service will often not be utilized.

It appears that ideally a service should be planned with an awareness of all four needs. In relation to this project it is felt that the community planning process has generally reflected the normative needs. This study will therefore attempt to define the felt needs of the consumer on a broader basis than committee representation because it is believed that it is essential to have an understanding of what the parents, who will be the users of the service,

see as important and in fact, establish if there are any differences between the community's conception of an ideal service and the consumer's i.e., (parents of Category III, Level C children) conception of the same kind of service.

The interest in this kind of study was also stimulated by this writer's involvement on one of the community planning committees that formed part of the structure of phase II of the Calgary Plan. As a result of this involvement interaction occurred with both parents and professionals in this field, and often conflicting perceptions of need and philosophies seemed to emerge. It was a desire to test some of the writer's own suppositions that prompted this study.

#### Population and Sample

The number of children and adults in Calgary who are severely/profoundly retarded, (Level C) in their classification, number 523. Of this number, 91 reside in their own homes, 151 are located in the Ash-Deerhome residence in Red Deer, 24 are in one of several different kinds of hospitals, and 167 are in Baker Centre. Of this total, group it is estimated that 79 have extensive nursing and health care needs (Category III).<sup>7</sup> It is this particular population that is not only severely to profoundly mentally handicapped (Level C) but also extensively physically handicapped (Category III) that constitutes the population to be studied. This population reside with their parents or in institutions and guardianship is either retained by their parents or is held by the government.

Unlike the Edmonton Region Division of Services for the Handicapped, Department of Social Services and Community Health, which has

a registry of children and adults in Edmonton who fall into specific categories, Calgary has no central registry or exhaustive list of the mentally handicapped, nor does it have a list that differentiates according to the level of handicap or health care service that is required. When the census data was compiled for Phase I of the Calgary Plan a listing was made of all the population in various categories of handicap including the 79 severely/profoundly retarded with extensive health care needs. At the time this census was taken, anonymity was assured to the guardians of this population. The listings were coded in to a computer and all raw data census sheets were destroyed; thus to obtain an exhaustive sampling frame all agencies would have had to be approached once again for their co-operation in identifying this population as well as assisting with the survey. Rather than repeating this procedure it was decided to use a non-probability sampling plan with a purposive or judgmental sampling method; i.e., one agency was chosen, specifically, "Services for Handicapped Children" because it appeared to be the agency with the largest single listing of Level C clients with extensive health care needs. This sample was chosen because of the nature of its constitution in reference to the writer's aims.

Non-probability sampling was necessary because the boundaries of the entire population were unknown. The 79 listed in the census data were delineated because of a contact with a service of some type; however because of the lack of a central registry, at a time, such as birth, this number may not reflect the total population; although it will reflect the total population involved with some kind of service.

The specific sample used for this research consisted of the list of severely/profoundly retarded individuals with extended health care needs registered with Handicapped Children's Services.

#### Research Design and Method of Observation

The design used in this study was a survey and the method of observation was a direct response questionnaire. This method was chosen because it was felt that this instrument was best suited to the purpose of the study which was to elicit the broadest range of ideas from the parents of handicapped children. It was hoped that the implications of this exploration would provide data for future research.

The questionnaire was distributed to the social workers at Handicapped Children's Services who contacted the qualifying families by telephone to inform them of the questionnaire. This was followed by a personal delivery of the questionnaire by the social worker. A self-addressed, stamped envelope was included with the questionnaire.

Pretests were conducted with both parents and professionals in the field. The suggestions and modifications made by these people were included in the final draft. In all, 55 children were studied. Of these 21 completed questionnaires were returned. The survey questionnaire focussed on the parents' perception of the needs of their children in terms of programming and residence. It did not attempt to validate the accuracy of the parents' perceptions.



## NOTES TO CHAPTER V

1. Writers such as Wolfensberger, Kugal and Dybwad document these findings. These and other authors are discussed in Chapters II and III.
2. Normalization has been succinctly described as "letting the mentally retarded obtain an existence as close to the normal as possible." This concept is dealt with in more detail in Chapter II.
3. Jonathan Bradshaw, "A Concept of Social Needs," New Society, March, 1972, Vol. 30 p. 640.
4. Anthony Forder, Concepts in Social Administration, London: Routledge and Kegan Paul, 1974, pp. 39-57.
5. Ibid, p. 51.
6. Bradshaw, p. 641.
7. Division of Services for the Handicapped, Department of Alberta Social Services and Community Health, Technical Supplement, Calgary, Alberta: The Division, 1974.

## CHAPTER VI

### FINDINGS FROM THE SURVEY

In this chapter the writer will explore the needs of the study population as perceived by the parents in relation to program and residential services. This chapter has three divisions. The first is a description of the sample; the second is a description of the parents' perception of their childrens' needs. The third describes the interaction between three descriptive variables or more than one descriptive variable and a perception variable.

#### Description of the Sample

The children selected for this survey were all those who were categorized as Level C with extended health care needs (Category III) and who were registered at Handicapped Children's Services, Calgary division. The word children, regardless of age, has been used because the respondents to the questionnaire were all parents.

#### Response to Survey

The survey was conducted in May and June 1978. The study universe consisted of sixty-seven children who fell into the specified category.

Fifty-five questionnaires were sent out and twenty-one were returned which was a 38% response rate. The additional twelve families did not receive questionnaires due to the difficulty in locating them.

TABLE I

TOTAL PARENTAL RESPONSE TO  
QUESTIONNAIRE ON DEPENDENT  
HANDICAPPED CHILDREN

<u>Parental Response</u>	<u>Number</u>	<u>Percentage</u>
Questionnaires Returned	21	38
Questionnaires Not Returned	34	62
Total	55	100%

PARENTS NOT CONTACTED = 12

The Calgary region was the study area. Eighteen parents lived in Calgary and three in the surrounding region.

Sample Identification

By Sex of Children

The population identified by the replies had 12 males and 9 females. See Table 2.

TABLE 2

SEX OF CHILDREN

<u>Sex</u>	<u>Number</u>	<u>Percentage</u>
Males	12	57
Females	9	43
Total	21	100%

By Age and Sex of Children

The distribution of the sample according to the age and sex of child is set out in Table 3.

TABLE 3

DISTRIBUTION BY AGE  
AND SEX OF CHILDREN

<u>Age in Years</u>	<u>NUMBER</u>		
	<u>Male</u>	<u>Female</u>	<u>Total</u>
0-5	3	2	5
6-10	2	1	3
11-15	4	4	8
16-20	3	2	5
Totals	12	9	21

By Place of Birth

The place of birth was obtainable for all twenty-one children and showed that twelve were born in Calgary, three in Edmonton, two in Taber, one in Medicine Hat, one in Lethbridge, one in Hanna, and one in Mayerthorpe. All children were, therefore, born in Alberta.

Program Attendance by Sex of Children

Of the children in the survey seventeen attended a program for dependent handicapped while two did not attend. Two parents never responded to the question. See Table 4.

TABLE 4  
ATTENDANCE IN A PROGRAM  
BY SEX OF CHILDREN

<u>Attendance in Program</u>	<u>Male</u>	<u>Female</u>	<u>Total</u>
Yes	9 ( 82%)	8 (100%)	17 (89%)
No	2 ( 18%)	0	2 (11%)
Total	11 (100%)	8 (100%)	19 (100%)

No Response = 2

The main effects of Table 4 show there are a greater number of children in a program than not and that there are more males than females in the sample. The interactive effects of Table 4 show:

1. There are a greater proportion of females in programs than males (100% to 82%).
2. There are a greater proportion of males not in programs than females (18% to 0), in fact there are no females who are not in a program.

In reference to the two children who were not in programs; they had been in a program but were withdrawn because of transportation problems. One parent specifically indicated that her child's respiratory condition was frightening to the handi-bus driver.

#### Place of Residence by Sex of Children

Of the children in the survey, five were residing at home and sixteen were residing away from home. Of the sixteen that were living away from home, two were residing with other families and fourteen were in a residence for the handicapped. See Table 5.

TABLE 5

PLACE OF RESIDENCE  
BY SEX OF CHILDREN

<u>Place of Residence</u>	<u>Male</u>	<u>Female</u>	<u>Total</u>
At Home	4 ( 33%)	1 ( 11%)	5 ( 24%)
Away From Home	<u>8 ( 67%)</u>	<u>8 ( 89%)</u>	<u>16 ( 76%)</u>
Totals	12 (100%)	9 (100%)	21 (100%)

A main effect of Table 5 shows that the greatest number of handicapped children reside away from home. The interactive effects of Table 5 show:

1. A greater proportion of males than females live at home (33% to 11%).
2. A greater proportion of females than males live away from home (89% to 67%).

By Marital Status of Parents

Of all the parents who responded three were divorced, seventeen were married and one couple did not respond to the question. See Table 6.

TABLE 6

MARITAL STATUS OF PARENTS

<u>Marital Status</u>	<u>Number</u>	<u>Percentage</u>
Single	0	0
Divorced	3	15
Separated	0	0
Married	17	85
Widowed	<u>0</u>	<u>0</u>
Total	20	100%

No Response = 1

By Income Level

The population contained four families with incomes below ten thousand dollars, eight with income between \$10,000 and \$19,999, four with income between \$20,000 and \$29,999; one with an income level between \$30,000 and \$39,999 and three families with income over \$40,000. See Table 7.

TABLE 7

INCOME LEVELS OF FAMILIES WITH  
DEPENDENT HANDICAPPED CHILDREN

<u>Income Level</u>	<u>Number</u>	<u>Percentage</u>
under \$10,000	4	20
\$10,000 - \$19,999	8	40
\$20,000 - \$29,999	4	20
\$30,000 - \$39,999	1	5
\$40,000 & over	3	15
Total	20	100%

No Response = 1

Parents' Perception of the ProblemParents' Perception of Degree of Child's Handicap

All the children in the study were identified by professionals as being profoundly or severely handicapped. This was generally reflected in the parents' perception of the handicap. Sixteen saw their children as severely retarded; four saw their child as profoundly retarded and one saw their child as moderately retarded. See Table 8.

TABLE 8

PARENTS' PERCEPTION OF DEGREE OF  
CHILD'S HANDICAP BY SEX OF CHILD

<u>Degree of Handicap</u>	<u>Male</u>	<u>Female</u>	<u>Total</u>	<u>Percentage</u>
Mild	0	0	0	0
Moderate	1	0	1	5
Severe	10	6	16	76
Profound	1	3	4	19
Total	12	9	21	100%

Parents' Perception of Child's Health Condition

All the children in this sample were identified as having related health problems by the professionals. This was not always reflected in the parents' perception of their child's condition. Fifteen parents saw their children as having related health problems. Five parents felt their child had no related health problems and one family did not respond to the question. See Table 9.

TABLE 9

PARENTS' PERCEPTION OF HEALTH  
CONDITION BY SEX OF CHILD

<u>Presence of Health Condition</u>	<u>Male</u>	<u>Female</u>	<u>Total</u>	<u>Percentage</u>
Yes	10	5	15	75
No	2	3	5	25
Total	12	8	20	100%

No Response = 1



Parents' Perception of Need for Professional Health Service

Of the children in the sample who were perceived as having related health problems by their parents; three parents saw their children as always needing the service of a professional health person, four as needing the service very often, five as requiring the service about as often as not, three seldom requiring the service and one never requiring the service. See Table 10.

TABLE 10

PARENTS' PERCEPTION OF THE NEED FOR THE  
SERVICES OF A PROFESSIONAL HEALTH  
PERSON BY SEX OF CHILD

<u>Amount of Service Required</u>	<u>Male</u>	<u>Female</u>	<u>Total</u>	<u>Percentage</u>
Always	3	0	3	19
Very often	2	2	4	25
About As Often As Not	3	2	5	31
Seldom	1	2	3	19
Never	1	0	1	6
Total	10	6	16	100%

Parents' Perception of Adequacy of Services for the Dependent Handicapped

There was a diversity of opinion in regard to the adequacy of service provided for the dependent handicapped. Six parents felt service provision was adequate, eleven felt service was somewhat adequate, i.e., there was room for improvement, and four felt the service was inadequate. No one listed service as being grossly inadequate. The major proportion of respondents felt the service was somewhat adequate. See Table 11.

TABLE 11

PARENTS' PERCEPTION OF THE ADEQUACY  
OF SERVICE BY SEX OF CHILD

<u>Adequacy of Service</u>	<u>Male</u>	<u>Female</u>	<u>Total</u>
Adequate	2 ( 17%)	4 ( 44%)	6 ( 29%)
Somewhat Adequate	7 (58%)	4 ( 44%)	11 ( 52%)
Inadequate	3 ( 25%)	1 ( 12%)	4 ( 19%)
Grossly Inadequate	0 ( 0 )	0 ( 0 )	0 ( 0%)
Total	12 (100%)	9 (100%)	21 (100%)

The interactive effects of Table 11 are as follows:

1. A greater proportion of parents with female children felt the service was adequate; as opposed to parents with male children.
2. A greater proportion of parents with male children felt the service was somewhat adequate.
3. A greater proportion of parents with male children felt the service was inadequate.

There was a variety of comments from parents in reference to areas of improvement. Several stressed the waiting lists for residential accommodation as an immediate concern, as well as stating that most residential facilities were located out of the community which placed an added hardship on families. Comments were also made about the lack of qualified and sufficient numbers of staff as well as a lack of emphasis on teaching and training within residential facilities. One parent made reference to the lack of a home-like residence for this population and another strongly cited Michner Centre in Red Deer as being an example of an extremely inadequate situation for the dependent handicapped.

Parents' Perception of the Appropriateness of Programs

Of the seventeen children that were in a program thirteen parents felt it was appropriate, while three felt it was inappropriate for their child's needs and one parent was undecided. The greatest proportion of parents with children in programs felt the programs were appropriate. See Table 12.

TABLE 12

PARENTS' PERCEPTION OF THE APPROPRIATENESS  
OF THE PROGRAM BY SEX OF CHILD

<u>Program</u>	<u>Male</u>	<u>Female</u>	<u>Totals</u>
Appropriate	7 ( 78%)	6 ( 75%)	13 ( 76%)
Inappropriate	1 ( 11%)	2 ( 25%)	3 ( 18%)
Undecided	1 ( 11%)	0	1 ( 6%)
Total	9 (100%)	8 (100%)	17 (100%)

No Response = 4

The interactive effects of Table 12 are as follows:

1. A greater proportion of parents with male handicapped children felt the program was appropriate than parents with female children; although the difference is so small as to be almost negligible.
2. A greater proportion of parents with female children as opposed to male children felt the programs were inappropriate (25% to 11%).
3. A greater proportion of parents with male children were undecided.

Of the three parents who felt the program was inappropriate for their child's needs, one parent felt the class was too large; another felt that the program did not run long enough and that it should be increased from two days to four. The third parent felt that there

was too much time spend being sympathetic and not enough time spent on good learning.

Parents' Perception of Difficulty Involved  
In Caring For Their Child At Home

Of the five children in the survey who were living at home, one parent felt the caring for the child was not difficult, one parent found it somewhat difficult, while three parents found it very difficult. See Table 13.

TABLE 13

PARENTS' PERCEPTION OF DIFFICULTY OF CARING  
FOR THEIR CHILD AT HOME BY SEX OF THE CHILD

<u>Amount of</u> <u>Difficulty</u>	<u>Male</u>	<u>Female</u>	<u>Total</u>
Not Difficult	1 ( 25%)	0 ( 0)	1 ( 20%)
Somewhat Difficult	0 (0)	1 (100%)	1 ( 20%)
Very Difficult	3 ( 75%)	0 (0)	3 ( 60%)
Breaking Point	0 (0)	0 (0)	0 (0)
Total	4 (100%)	1 (100%)	5 (100%)

A main effect of Table 13 indicates the greatest number of parents caring for their handicapped child at home found it very difficult.

The interactive effects of Table 13 indicate:

1. A greater proportion of parents with male children than female found caring for their child "not difficult" and "very difficult."
2. A greater proportion of parents with female children than male found caring for their child at home "somewhat difficult."

Four of the parents who were caring for their child at home indicated that they anticipated a time when they would require the care provided by a special residence. One parent of a male child

indicated that they were uncertain if they would require a special residence. This uncertainty was based on whether or not the child became too heavy to manage.

Comments in terms of what parents would like to see available to their child were fairly consistent. Two parents mentioned a home-like situation with four to six persons per sleeping unit. Two parents mentioned outside recreation such as swimming, as well as a basic training program. One parent mentioned daily physiotherapy and occupational therapy, and nurses and doctors who are specialists rather than generalists. One parent also mentioned personal attention and love.

#### Parents' Satisfaction With The Care in the Residence

Of the fourteen parents who had children residing in residence, all fourteen indicated they were satisfied with the care. One commented on the excellence of the feeding program at the Baker Sanitorium. Two other parents qualified their satisfaction somewhat. One indicated that the distance and expense to get to Michner Centre in Red Deer was a problem, while another indicated that she had a second retarded child who did not fit into this particular survey population but who was in Red Deer, and she was very dissatisfied with the care there.

#### Parents' Perception of Considerations in Planning a Residential Facility

##### Physical Comfort

There were many different ideas expressed by parents, but most were fairly consistent. Six parents mentioned special furniture and

equipment that would assist their handicapped child. Four parents mentioned a cozy, homelike atmosphere, that had provisions for safety. Another three parents mentioned they would like to see two per bedroom as well as recreational facilities. Two parents mentioned they would like to see the building bright and clean and one-storey in height. Other comments included proper food, as normal environment as possible, dry clothing and beds and fresh air daily.

#### Individualization

At least eleven parents felt the most important factor to consider under individualization was that their children should receive personal attention, preferably in small groups. Associated with this idea was that programs should be individually and developmentally based, where children were trained to reach their potential.

Two parents felt there should be private rooms and individual sleeping units; whereas another parent felt that individualization could be achieved through "semi-private wards."

Three parents commented that the special equipment and toys should be geared to the individual needs of the child. Two parents felt children should have their own clothes and belongings.

#### Location of Facility

Comments on location were extremely consistent. Eight parents indicated the facility should be located within the community in order to cut back on transportation problems. Seven parents stated that the residence should be regionally-based i.e., children from Calgary should be placed in Calgary and not in Red Deer or Edmonton. Two other parents used words such as "residential" and "quiet

location" to express their thoughts. Four parents felt the residence should be located on the periphery of the community.

#### Ideal Size of Facility

Comments on the size were very diverse. Four parents indicated that it should be structured in such a way that small groups would exist in a large centre. Three parents felt that small, home-like units of approximately 8-10 persons should be built. Two parents felt the units should only contain five to six residents. Three parents felt the appropriate numbers should be: (1) 12 -18; (2) 50; and (3) 75 - 100. Another parent felt a duplex would make the ideal residence. Two parents commented that the size did not matter and that the main considerations should be programming and relief bed space.

#### Staff

The question on staff drew the most comments from the respondents. Eight parents indicated that staff working with this level of child should be "caring, patient, compassionate, and understanding." Five parents mentioned the importance of screening procedures, in-service training, and evaluation. Only three parents mentioned the medical component; one felt visiting nurses would be adequate, another felt 24 hour nursing care was required and a third felt there was a need for a medical back-up service.

Other qualities that were stressed by parents were as follows:

- "the ability to treat the handicapped as normally as possible
- ability to learn how to care for the medical problems
- good health
- disciplined and task orientated."

One parent stressed the importance of the continuity of care, i.e., that one child should have a continuously involved staff person, whereas another felt there should be a continuous change in order to avoid the loss of attachment. One parent also mentioned the importance of having enough staff to meet the personal attention needs of the children.

#### Special Care Needs

Twelve of the parents felt the special care needs should be met by both the specialists and generalists in the community; six felt the needs should be met by specialists only and one parent felt that these needs should be met only by generalists. Two parents did not respond. See Table 14.

TABLE 14

#### PARENTS' PERCEPTION OF WHO SHOULD MEET THE SPECIAL CARE NEEDS OF THE RESIDENTS

	<u>Total</u>	<u>Percentage</u>
Specialists	6	32
Generalists	1	4
Both	12	64
	<hr/>	<hr/>
Total	19	100%

No Response = 2

Comments by the parents were fairly consistent. The majority of parents mentioned that specialists should head the staff and that general services should operate under the specialists. One parent felt specialists alone should be involved due to the general lack of knowledge of the community at large as well as the medical



profession in relation to this level of handicap. Another parent felt that specialists should be in charge of any program involving learning; whereas generalists could assume other services such as dental.

The one parent indicating that generalists should be the main service provider stated that this would help others learn how to cope with the handicapped. In other words, it would be an educational device.

#### Program Integration within the Community

Of the twenty-one respondents to the survey, twelve felt the program should be integrated into the community, four felt it should not, two were uncertain and three did not respond to the question. See Table 15.

TABLE 15

#### PARENTS' PERCEPTION OF PROGRAM INTEGRATION IN THE COMMUNITY

	<u>Total</u>	<u>Percentage</u>
Yes	12	67
No	4	22
Uncertain	2	11
Total	18	100%

No Response = 3

Those who did not favour integration cited such factors as the unacceptance of the community as the reasoning. The concept of sheltering the handicapped was reflected.

### Separation by Age

Of those people surveyed, eleven felt that children and adults in this population should be separated by age; eight felt they should not and two did not respond to the question. See Table 16.

TABLE 16

#### PARENTS' PERCEPTION OF SEPARATION OF CHILDREN AND ADULTS

	<u>Total</u>	<u>Percentage</u>
Yes	11	58
No	<u>8</u>	<u>42</u>
Total	19	100%

No Response = 2

Two parents who felt there should be a separation cited the fact that people should associate with their own age. Two other parents felt the separation should occur because of the possible harm the adults could do to the children.

Of the eight parents who felt there should not be a separation by age, six felt there should be a separation based on degree and type of handicap. One other parent expressed the idea that separation worked against integration and the "family" concept where all ages lived together.

#### Parents' Perception of Servicing All Levels of Handicap in the Same Geographic Area

Of the twenty-one respondents nine felt that all levels of handicap should not be serviced in the same area, seven felt they should, three were uncertain and two did not respond to the question.

TABLE 17

PARENTS' PERCEPTION OF SERVICING  
ALL LEVELS OF HANDICAP  
IN SAME GEOGRAPHIC AREA

	<u>Total</u>	<u>Percentage</u>
Yes	7	37
No	9	47
Uncertain	<u>3</u>	<u>16</u>
Total	19	100%

No Response = 2

One parent commented that she felt they should be serviced in the same area in order to facilitate transportation arrangements.

Those who felt all handicapped should not be serviced in the same area commented on "overloading" a community with deviant people and therefore lowering acceptance of them. One parent felt that there could be a greater awareness of the handicapped because of the exposure that scattering them could bring.

#### Parents' Perception of the Administration of the Facility

The perception of who should administer the facility was widely varied. One parent felt it should be administered by a Community Board, two by a Parent Association, four by the Government, one by a Parent Association and the Government, one by the Government and a Community Board and three by a Community Board and a Parent Association. Five felt it should be administered by a combination of all three and four had no opinion. See Table 18.

TABLE 18

PERCEPTION OF WHO SHOULD  
ADMINISTER RESIDENTIAL FACILITY

	<u>Total</u>	<u>Percentage</u>
Community Board	1	6
Parent Association	2	12
Government	4	23
Parent Association & Government	1	6
Community Board & Government	1	6
Community Board & Parent Association	3	18
Community Board, Parent Association & Government	<u>5</u>	<u>29</u>
Total	17	100%
No Response = 4		

Additional Perceptions

Several parents took the opportunity to comment in the space provided. Some made comments in regard to possible service provisions and others shared some of their feelings.

In terms of service provision, suggestions such as emergency wards staffed with persons knowledgeable about handicaps; prohibition of smoking in areas where there are handicapped and information and counselling services for parents were suggested.

Other parents commented on their concern about the future as well as the sorrow and joy involved in having a retarded child. One

parent felt a study should be done that would explore the effects of a retarded child on a couple as well as the siblings - "who sometimes are more damaged and most often a lot less happy than the child--the martyred, those turned insensitive, defeated, guilt ridden, resentful, the broken-hearted." One parent took the opportunity to comment on her satisfaction with the care at the Baker Sanitorium.

### Interaction Between Variables

#### Health Condition, Age and Sex

TABLE 19

#### PARENTS' PERCEPTION OF HEALTH CONDITION BY AGE AND SEX OF CHILD

Age	Male		Female		Total
	Health Condition	No	Health Condition	No	
0-5 yr.	3	0	2	0	5
6-10 yr.	2	0	0	0	2
11-15 yr.	3	1	2	2	8
16-20 yr.	2	1	1	1	5
Total	10	2	5	3	20

No Response = 1

The main observations from Table 19 are as follows:

1. There are more males in the sample than females (12 males; 8 females).
2. The greatest number in the sample are in the 11-15 year age range.
3. There are more individuals perceived as having health problems than not (15-5).

The interactive effects of Table 19 are more easily visible in three bivariate tables:

- (a) Age by sex, which has been delineated in Table 3
- (b) Age by health condition (See Table 20)
- (c) Sex by health condition (See Table 21)

TABLE 20

NUMBER OF DEPENDENT HANDICAPPED CHILDREN  
BY AGE AND PERCEIVED HEALTH CONDITION

<u>Age (In Years)</u>	<u>Health Problems</u>	<u>No Health Problems</u>	<u>Totals</u>
0-5	5 ( 33%)	0 (0%)	5 ( 25%)
6-10	2 ( 14%)	0 (0%)	2 ( 10%)
11-15	5 ( 33%)	3 (60%)	8. ( 40%)
16-20	<u>3 ( 20%)</u>	<u>2 (40%)</u>	<u>5 ( 25%)</u>
Total	15 (100%)	5	20 (100%)

The interactive effects are as follows:

1. A greater proportion of those children between 0 and 10 years have health problems than do not have health problems, in fact, all children between 0 and 10 years are perceived as having health problems.
2. A greater proportion of those children between 11 and 20 years have no health problems than have health problems.

TABLE 21

NUMBER OF DEPENDENT HANDICAPPED CHILDREN  
BY SEX AND PERCEIVED HEALTH CONDITION

	<u>Health Condition</u>	<u>No Health Condition</u>	<u>Total</u>
Male	10 (83%)	2 (17%)	12 (100%)
Female	<u>5 (63%)</u>	<u>3 (37%)</u>	<u>8 (100%)</u>
Total	15	5	20

The interactive effects of Table 21 are as follows:

1. A greater proportion of males than females have health problems.
2. A greater proportion of females than males do not have health problems.

By Place of Residence, Age and Sex

TABLE 22

PLACE OF RESIDENCE OF DEPENDENT  
HANDICAPPED CHILD BY AGE AND SEX

AGE	MALE		FEMALE		TOTAL
	At Home	Away	At Home	Away	
0-5 yr.	2	1	0	2	5
6-10 yr.	0	2	0	1	3
11-15 yr.	0	4	1	3	8
16-20 yr.	<u>2</u>	<u>1</u>	<u>0</u>	<u>2</u>	<u>5</u>
Total	4	8	1	8	21

This table illustrates three two-way interactions:

- (a) Place of residence by age (See Table 23)

(b) Place of residence by sex which is set out in Table 5

(c) Age by sex which is set out in Table 3

TABLE 23

NUMBER OF DEPENDENT HANDICAPPED CHILDREN  
BY PLACE OF RESIDENCE AND AGE

<u>Age (In Years)</u>	<u>At Home</u>	<u>Away</u>	<u>Total</u>
0-5	2 ( 40%)	3 ( 19%)	5 ( 24%)
6-10	0	3 ( 19%)	3 ( 14%)
11-15	1 ( 20%)	7 ( 43%)	8 ( 38%)
16-20	2 ( 40%)	3 ( 19%)	5 ( 24%)
Total	5 (100%)	16 (100%)	21 (100%)

The interactive effects of Table 23 are as follows:

1. A greater proportion of children between 0 and 5 years and 16-20 years reside at home compared to away from home.
2. A greater proportion of children between 6-10 years and 11-15 years reside away from home compared to at home.

### Summary

In this chapter, the data from the survey has been summarized and the interactions between some of the study variables have been mentioned. Some of the implications of this data will be discussed in the next chapter.



## CHAPTER VII

### DISCUSSION OF FINDINGS

This study has been exploratory in approach and has described how parents perceive the programming and residential needs of their children.

In the following discussion of the findings an effort will be made to interpret some of the information as well as some theorizing about some of the possible parental reasoning. In addition, some discussion will take place in reference to the parents' recommendations and how these are related or not related to the principles of normalization. The population studied revealed almost an equal split between the sexes; twelve boys and nine girls were examined.

All children in the sample were born in Alberta. The lack of mobility among parents of dependent handicapped appears significant considering the number of families. It is possible to speculate that a handicapped child does limit a family's mobility. Once services have been identified and are being utilized, particularly in the case of residential services, that family is probably reluctant to search for resources elsewhere or sever ties further with their child.

A large percentage of the parents (85%) in the study were still married and living together. This is significant considering much of the literature in the field which has speculated as high as 50% divorce rates in families with handicapped children.<sup>1</sup>

All the children in the study had been diagnosed as Level C, i.e., severely or profoundly retarded and the majority of parents (with only one disagreeing) seemed able to accept this classification. This is significant in terms of the reality of working with the parents in the planning of care for their child.

The findings about the child's health condition as well as the need for professional health services were particularly interesting in view of the difficulty the committee had in reaching an understanding of whether or not these children were physically "sick," i.e., did they need the constant attention of a professional health person? Although all the children were professionally diagnosed as having related health problems only 75% of the parents perceived them in this fashion. Of these parents, the majority felt their child needed health services "about as often as not." This appears to reinforce much of what is being said in the field today that all of this population is definitely not sick nor in need of health services all the time. There appears to be a health stabilization factor with these children.

The data also indicates that the greatest proportion of the children perceived as having health problems are between 0 and 10 years of age and the greatest proportion of the children perceived as having no health problems are between 11 and 20 years. This finding seems to carry definite implications in terms of service delivery. Health services are a definite necessity in the early years of a child's life, but if a child lives past 10 years then generally a different type of care may be needed for this child.

The data also reveals that a greater proportion of males than females are perceived as having health problems. This could be significant in that a greater proportion of males also reside at home where parents are constantly exposed to their child's needs.

The findings relating to adequacy of service revealed that the largest majority of parents felt that services could be improved. Parents with female handicapped children were more inclined to view service as adequate than parents with male children. There could be two possible reasons for this. One could be culturally related to the expectations associated with males in terms of knowledge, learning and training. The second could be related to the fact that more female children were residing outside the home and as a result there may have been less urgency with these parents.

The number of children in the survey who are in a program is reflective of the efforts that have been made towards this population. Of all the parents in the study only two had children who were not in a program. These two were male children residing at home, who had been in a program, but were withdrawn because of transportation problems. It can be concluded that those living at home are presently at a disadvantage in terms of day services. This has definite implications for planning activities. If parents of handicapped children are going to be encouraged to keep their children at home, then improvements in transportation and location of facilities must be planned. Children residing at home should not be at a disadvantage.

Generally, parents were satisfied with the suitability of the program for their child (76%). It does not seem unreasonable, however, to speculate that parents are largely uncritical of the

programs because of the relief it affords them. Parents with female children had a greater tendency to view programs as inappropriate than parents with male children. It is difficult to speculate on the reason for this other than more female children are in programs and reside away from home.

Related to the place of residence the data revealed that the largest portion of handicapped children were residing away from home (76%). There was also a greater tendency for males to live at home. This again could be due to cultural factors. It is perhaps more stigmatizing and threatening to give up a male child who in some ways is responsible for the continuation of that family. There may be less difficulty acknowledging and accepting the retardation of a female child.

Tied in with this is the relationship between age and place of residence. The greater proportion of very young children (0-5 yr.) and older children (16-20 yr.) tended to reside at home, while a greater proportion of the "middle" range i.e., (6-15 years old) tended to reside away from home. This has definite implications for planning activities. It appears that many families, initially keep their child before making some decision concerning their child's future. If a child is not institutionalized by the time he reaches 16 years of age, it seems reasonable to assume that the family will attempt to care for him as long as they are able.

The finding relating to the difficulty associated with caring for a handicapped child at home is also significant in terms of planning. The greatest portion of parents found the task "very

difficult." It is not unlikely to assume that at some point all parents of this level of child will be requesting institutionalization and this is a definite factor that must be considered by the planners in designing the space in any kind of residential situation.

Question: 10, requesting parents to comment on what they considered important factors to take into account on a number of dimensions associated with a residential centre was specifically designed to acquire an understanding on how parents felt towards a number of basic normalization principles.

Physical comfort under normalization guidelines strives to ensure comfort. It is believed that the quality of the physical setting is reflective of the people using it and has a great deal to do with either positive or negative image association. This does not preclude special equipment necessary to meet the needs of a particular population. The parent's perceptions of what would provide good physical comfort did stress these normalization principles. Variables such as appropriate and comfortable furniture and equipment, coziness and cleanliness were often mentioned. Generally speaking it appeared that parents perceived the ideal facility as that which provided comfort, as close to normal as possible.

Within the parameters of normalization, individualization reflects how persons are recognized as different from one another and how they are encouraged to express themselves. In terms of the dependent handicapped individualization refers to such factors as programming and equipment according to assessed needs as well as sufficient staff so that all can receive personal attention. Privacy

personal territory, and restrictions carry great implications in terms of individualization. Parents, in the survey, consistently concurred with this part of the normalization philosophy. "Personal attention, small groups, privacy, individual programs, private or semi-private sleeping units" were considered important factors by parents.

Normalization maintains that both proximity and access are important principles to consider in deciding upon the location of a facility. If a facility is isolated, distance creates a barrier to both the physical and social integration as well as producing an effect upon the way the clients are identified by the community.

The parents in the survey were very consistent in this respect. The greatest proportion felt that the facility should be located within a community and not on the periphery. In addition, the fact that many parents stressed the need to regionally base the service is an indication of how they perceived the importance of access.

In terms of the size of a facility, normalization generally proposes that the larger the structure, the greater the difficulty in achieving integration. In terms of the dependent handicapped a concern in terms of creating a large structure is the threat that staff will move towards a controlling custodial rather than a caring role. Associated with this principle is the idea that buildings should match the program or activity being offered in it.

This question, more than any other brought the greatest diversity of responses from the parents surveyed. The largest proportion of them indicated that it should be a large structure

with small groups inside. Other recommendations varied from small group homes to large institutions. Normalization implies that integration is generally inversely affected by size, however it also implies that buildings must match the activity within. It is this writer's supposition that "small groups within a large centre" would fall below the halfway mark towards normalization. It appears that more normative thinking would encompass small units with a larger back-up facility.

Normalization proposes that staff selection is extremely important. Persons who value themselves tend to create positive environments as well as positive image associations. In addition, continuity of staff is regarded as important in terms of supporting individual expression of need. The parents in the survey concurred with this principle. The quality of the people working with the children was stressed by every parent who responded. Training was seen as important but not more so than the human characteristics of the person.

Normalization maintains that the use of generic services is important for three reasons: segregation and stigmatization are minimized, agency barriers are broken and service duplication is reduced. The use of specialty back-up services is seen as essential but the goal is to acquire services through the same means as the public at large. This also has the added spin-off of public education. This philosophy was echoed by the largest proportion of parents who maintained that both specialists and generalists were required.

Normalization maintains that integration is a key concept and that how the public perceives the program will effect how much

integration occurs. If individuals are segregated by operating programs that do not afford any contact with non-handicapped then the chances of integration are reduced. Efforts must be made to create interactions in ways that are as normative as possible. The greatest proportion of parents surveyed concurred with this philosophy and maintained that program integration was important. Many of those who did not maintained the need to "shelter" the handicapped.

Normalization philosophy maintains that it is wrong to let mentally retarded children reside in the same institutions as mentally retarded adults. A normal life implies that childrens' environments should be rich in stimulation appropriate to children and likewise for adults. To attempt to meet the heterogeneous needs of both in the same institution is to compromise the needs of both according to the normalization thinkers. In terms of the dependent handicapped this principle carries significance in terms of the image transfer to the public. Children and adults residing together tend to reinforce a "little children" conception of the residents.

Parents, in the survey, largely agreed with this principle, although not by a wide margin (58% to 42%).

Normalization implies certain definite attitudes towards serving all the handicapped in the same geographic area. An important variable is the relationship between the number of handicapped individuals and the likelihood of their being absorbed by the community. Too many gathered in one area can cause "overload" and severe community reaction. Deviancy juxtapositions often increase community



negative reaction in general and thus any handicap can be perceived as greater than it is. In addition, negative stereotypes are more difficult to break down.

Parents in the survey concurred with this principle in that the majority maintained that all levels of handicap should not be serviced in the same area. It does appear, however, that this question was poorly worded as many parents seemed to have some difficulty understanding it.

Normalization maintains that consumer participation is essential in order to keep service vital and adaptive. This definitely seems to be reinforced by the parents in the survey through their responses to the question on the administration of the facility. The greatest majority felt that some consumer input was required either through community boards or parent associations. Very few parents felt that the government alone should be responsible.

In assessing the kind of service and facility recommended by the parents the prevalent attitude towards this population appears to be that of a "developing person." The majority of parents appear to want to see their child provided the opportunity to develop his potential within the confines of his handicap. Most want to see their child provided with an existence "as close to normal as possible," and as a result, they very much concur with the present thrust towards normalization in the field today.

### Summary

In this chapter some of the findings from the data have been discussed. In addition, the degree to which parents agree with normalization as a planning framework has been established.

## NOTES TO CHAPTER VII

1. Authors such as Roberta Robertson in her article, "Don't Speak to Us of the Living Dead," in Counselling Parents of the Mentally Retarded: A Source Book, ed. Roland Noland, (Springfield, Illinois: Charles C. Thomas, 1970), discusses the effect of the birth of a handicapped child on a family. In her study, fifty per cent of the families interviewed were separated or divorced.

## CHAPTER VIII

### IMPLICATIONS

In this chapter, the writer will look at the differences and similarities between the parents' perception and the community perceptions of needs (as reflected by the Special Care Residential for Children and Adults Committee) and the implications of this on service delivery.

From the data comes certain implications for service delivery, certain areas of concern regarding the differences between the normative needs expressed by the committee and the felt need expressed by the parents as well as certain reassurances regarding the community planning process as used in the Calgary Plan.

#### Implications for Service Delivery

##### Health Problems

As stated above, only 75% of the parents perceived their child as physically sick as opposed to 100% of the professionals who perceived them as "sick." In addition, of those perceived as having health problems, the greatest proportion required health service only "about as often as not." This is significant in terms of the planning process. To plan for this population on the traditional "at risk medical" basis with back-up for development appears to be overemphasizing the "disease" concept. The concepts of health and disease are accepted by key decision makers as having a significant influence on the philosophical orientation of any system. This influence is usually reflected in all aspects of a system's operation:

planning, delivery, management and evaluation.

It is felt by this writer that planning must start from a health concept rather than a disease concept and that the role and magnitude of the medical personnel involved in both the programming and service aspects for this population must be critically evaluated. There may have been a tendency to overemphasize the medical role in the committee's recommendations.

#### Programming

There appears to be a link between age and the presence of health problems. As stated earlier, the greater proportion of children with health problems were between the ages of 0 and 10 years. Those between 11 years and 20 years were more often perceived as having no health problems, implicating a health stabilization factor.

This writer proposes that the service network should consider the changing needs of this client population. Service must be flexible and adaptable if it is to meet the needs of this client group. There is some provision made for this in the planning of the committee through the provision of "streaming."

#### Transportation

As indicated earlier, children who were residing in the home appeared at a disadvantage in terms of attending day programming because of distance and transportation.

It is proposed by this writer that services should be regionally based within communities to allow for easier and quicker access by families and handicapped children. In addition, there should be

sufficient trained staff present in the transportation vehicles so no child will be without the benefit of a program because of the problem of going there. This could also be an area for future research in terms of addressing the question of whether or not this population should be transported.

#### Residential Care

A serious concern cited by parents was residential care. Many mentioned the waiting lists and the anxiety and fear of the lack of residential openings. In addition, most parents with children considered caring for the child "very difficult" It would seem reasonable to assume that all parents, with few exceptions, who have Level C and Category III children will eventually request that the ongoing care be assumed by an agency.

It is proposed that the planning of residential facilities should encompass a provision of space for all the children born in this category, i.e., Level C with health care needs, and not just a portion of them, in spite of the present trend which appears to indicate that placement is done in the "middle years" (i.e. 6-15 yr.) of a child's life.

#### Areas of Concern

In general there was quite a high degree of consistency between the recommendations of the committee and the needs as perceived by the parents. There were, however, some significant differences.

#### Health Problems

As dealt with earlier in this chapter the health problems as perceived by parents appeared to be less significant as those

perceived by the committee through their recommendations. Although the committee adopted a contingency plan in the event of health stabilization, the process of developing the building and staff structure appeared to emphasize the disease rather than the health aspects. In other words the planning seemed to reflect a building based on the "at risk" concept with a back-up for health; rather than a health concept with a back-up for the "at-risk" needs.

#### Generic Services

The Committee recommended the development of specialty services to deal with the problems of this population; whereas the parents' responses indicate that they feel the utilization of both are important. This difference could be quite significant in terms of community education.

#### Separation by Age

The committee proposed that the client population would be separate i.e., placed in one of the two fifty bed arms based on health need, rather than age. Parental responses indicate that separation by age is considered an important factor, and that this was not fully addressed by the committee.

#### Geographic Area

The committee recommended that a possible location for the residence could be near an acute care hospital. Parents responding to the survey most often indicated that different handicaps should not be serviced in the same area. This is quite a significant factor under normalization philosophy in terms of creating deviancy overload and inversely affecting integration.

Both the committee and the parents surveyed expressed the same indecisiveness over the size of the facility. Both recommended a large centre with small groups; however the committee experienced difficulty in arriving at this decision and the parental responses indicated almost as many different recommendations as there were parents responding. This does seem to suggest that this is an area for further research and a significant area in that it would probably affect the emphasis placed on the medical aspects.

#### Community Planning Process

To this writer, this study offers some reassurances regarding the community planning processes as used by the Calgary Plan. Many of the needs perceived by the parents and the committee were not atypical. Consumer representations most often reflected the feelings of the larger parent community, with some exceptions.

One spin-off to this planning process that has not been expressed through the Calgary Plan, but is believed to exist by this writer is that of fostering co-operation and co-ordination between agencies. This seems particularly significant to this writer in terms of what is interpreted as an historical lack of co-ordination between agencies in Calgary.

In spite of the fairly high degree of consistency between the committee's results and the parental survey, this writer feels that the omission of surveys of this type by the Calgary Plan has been an inherent weakness in the process. It is felt that parents must be involved regardless of the outcome if for no other reason than they are the future consumers. It is also felt that it would

be naive to conclude that because there has been a fairly high degree of consistency in this study that these results would be the same in the other twelve committees. In order to make such conclusions further research that would be designed to measure characteristics that contribute to consumer representation reliability would be required. In other words the role of characteristics such as group composition and chairmanship would have to be measured.

In addition, it is felt that future community planning bodies such as the Calgary Plan must have a broader mandate in terms of resources. This was a definite shortcoming in the process. In spite of these concerns this writer believes that the entire community planning process, with certain adjustments holds great promise in the field of social service planning.

In this study, the philosophies of both the committee and the parents were most often similar. The retarded are largely being perceived as "developing persons" and the planning is moving towards an adoption of normalization guidelines.



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## COMMUNITY REPRESENTATION

### COMMUNITY CO-ORDINATION

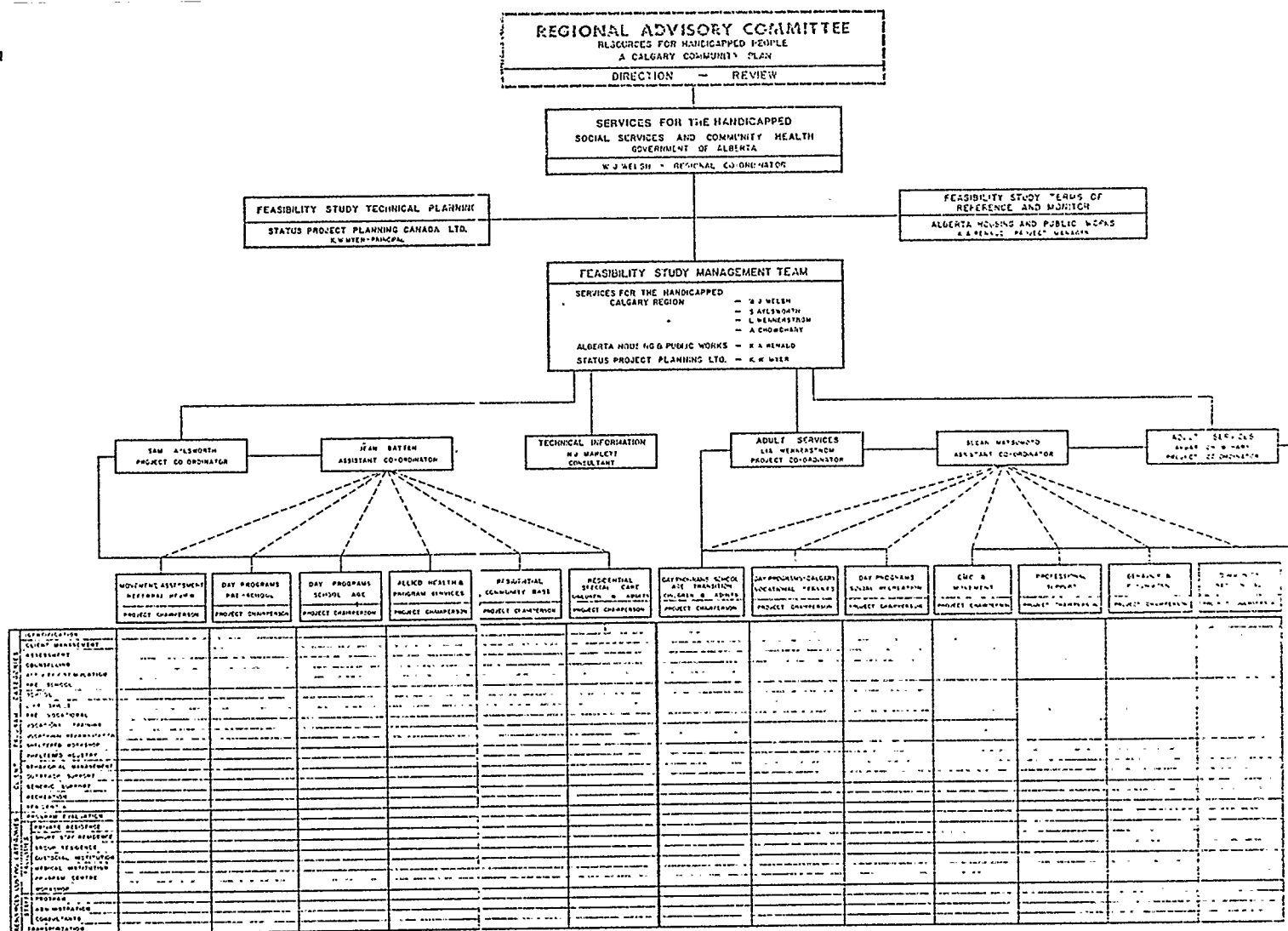
## TECHNICAL PLANNING

## PLANNING CONTROL

## PLANNING CO-ORDINATION

## SERVICE PROJECTS PLANNING

### RESOURCE DEFINITION



# FEASIBILITY STUDY-RESOURCE & COST SUMMARIES

## RESOURCES FOR HANDICAPPED PEOPLE

### A. CALGARY COMMUNITY PROJECT

Status Project Planning Canada Ltd.

SERVICE PROJECT: Special Care Residential

SUB-PROJECT: 1 - 10 bed module

PROGRAM CATEGORY: Residential

PROJECT CHAIRPERSON: John R. McDonald

THIS RESOURCE & COST SUMMARY REFERS TO THE FOLLOWING TARGET GROUP:

FUNCTIONAL LEVEL(S): 3

LEVEL(S) OF HANDICAP: C, D

AGE RANGE: CHILDREN: total population ADULTS: total population

#### CLIENT POPULATION

A. 1978 CENSUS, THIS TARGET GROUP	NO. <u>280</u>
B. NOT REQUIRING THIS (FUNDED) SERVICE	NO. <u>?</u>
C. REQUIRING THIS SERVICE	NO. <u>1077</u>
D. NOW ADEQUATELY STAFFED	NO. <u>—</u>
E. NOW INADEQUATELY STAFFED - REQUIRES ADDITIONAL STAFF	NO. <u>—</u>
F. REQUIRING NEW PROGRAMS AND NEW STAFF	NO. <u>150</u>
G. WHERE EXISTING FACILITIES APPROPRIATE	NO. <u>—</u>
H. WHO REQUIRE NEW FACILITIES - APPROPRIATE	NO. <u>1177</u>
I. WHO REQUIRE RENOVATED FACILITIES	NO. <u>—</u>
J. WHO REQUIRE TRANSPORTATION SERVICES	NO. <u>100</u>
K. INCLUDED FOR PROGRAM EVALUATION COSTING	NO. <u>100</u>

#### NOTES OF EXPLANATION:

1.  $A - B = C$ ,  $D + E + F = C$ ,  $G + H + I = C$ ,  $J = C$ ,  $K = C$  The number (No.) of clients shown in each category from "D" to "K" inclusive are part of the client population noted in box "C", but the categories are not mutually exclusive.
2. Functional Levels: Mild, Moderate, Severe to Profound.
3. Levels of Handicap: Developmentally Delayed, Physical Handicap, Health Care, Extended Care, Behavioral.
4. Age Ranges: Children Group 1 0- 5 years, Group 2 6-15 years.  
Adults Group 1 16-39 years, Group 2 40-60 years.

SERVICE MODULE	STAFF TYPE	NEW STAFF REQUIRED				YEAR	PROPOSED SERVICE PROVIDER(S)	
		SALARY OR RATE/HR.	NO.	% TIME OR HRS.	TOTAL COST		OPTION 1	OPTION 2
1-10 Bed module	Institutional aide	5.33/hr	10.5	2022.75	141,503.98			
residential	Nurse	7.37/hr	1.4		26,088.43		Crown Agency	Private Society
	Staff education	8.91/hr	1	10%	2,252.89		of Summary	of Summary
Formula:	Physician **		1	2.5%				
	Pediatrician **		1	4.5%				
Hr. rate x 2022.75	Speech therapist	8.09/hr		20% 22	204.47			
(hr. per year) = x	Social worker	8.09/hr	1	10%	2,045.56			
	Volunteer co-ordinator	8.91/hr	1	10%	2,252.89			
25% of x = y	Public Relationist							
	Psychiatrist **		1	1%				
	Orthopedic surgeon **		1	1%				
x + y = z (total cost per year)	Researcher Evaluation Consultant	8.91/hr	1	10%	1,126.45		1	1926,436.50
	Physiotherapist	6.96/hr	1	10%	87.96			
	*1 Occupational therapist	6.96/hr	1	2.13%	22.87			
(z)x(n) (total number)	nutritionist	9.85	1	10%	1,794.25		2	8884.80
= total cost	Administrator	12.36/hr	1	10%	3,125.28			
	Secretary	6.31/hr	1	10%	1,595.49		3	674,252.77
	Accountant/bookkeeper	8.18/hr	1	10%	2,068.31			
	Receptionist/secretary	5.64/hr	3		4,728.12			
	Personnel officers	8.97/hr	1	10%	2,269.06			
	Clerk	5.84/hr	1	10%	1,470.65			
	*2 Occupational therapist	7.44/hr		116 hr	3,868.8			
	Psychiatrist **			15.6 hr				
	Dentist **			20 hr				
	Pharmacist	9.14		500 hr	4520.00			
*1 for initial 6 month period	Orthodontologist **		GRAND	5 hr				
*2 after 6 month period	Orthodontics	7.20		50hr	360.00			
	Prosthetics	8.60		10hr.	86.00			
	Bill of Service Alberta Health							
	Totals							
	192,643.65 x 10							
	8884.80							
	674,252.77							
	2,609,574.07							
	+ 25% 652,393.50							
	Total 3,361,967.57							
	Other staff costs:							
	Dietary							
	Housekeeping							
	Laundry							
	Switchboard							
	Maintenance							
	Security							
	35% of TOTAL COST							
	674,252.77							
	Full Cost for 100 clients							

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# FEASIBILITY STUDY-RESOURCE & COST SUMMARIES

## RESOURCES FOR HANDICAPPED PEOPLE

### A. CALGARY COMMUNITY PROJECT

Status Project Planning Canada Ltd.

SERVICE PROJECT: Special Care Residential

SUB-PROJECT: Day Program

PROGRAM CATEGORY: Residential

PROJECT CHAIRPERSON: John R. McDonald

THIS RESOURCE & COST SUMMARY REFERS TO THE FOLLOWING TARGET GROUP:

FUNCTIONAL LEVEL(S): 3

LEVEL(S) OF HANDICAP: C, D

AGE RANGE: CHILDREN: total population ADULTS: total population

#### CLIENT POPULATION

- |  |                |
|--|----------------|
| A. 1978 CENSUS, THIS TARGET GROUP                          | NO. <u>280</u> |
| B. NOT REQUIRING THIS (FUNDED) SERVICE                     | NO. <u>7</u>   |
| C. REQUIRING THIS SERVICE                                  | NO. <u>100</u> |
| D. NOW ADEQUATELY STAFFED                                  | NO. <u>—</u>   |
| E. NOW INADEQUATELY STAFFED - REQUIRES<br>ADDITIONAL STAFF | NO. <u>—</u>   |
| F. REQUIRING NEW PROGRAMS AND NEW STAFF                    | NO. <u>100</u> |
| G. WHERE EXISTING FACILITIES APPROPRIATE                   | NO. <u>—</u>   |
| H. WHO REQUIRE NEW FACILITIES - APPROPRIATE                | NO. <u>100</u> |
| I. WHO REQUIRE RENOVATED FACILITIES                        | NO. <u>—</u>   |
| J. WHO REQUIRE TRANSPORTATION SERVICES                     | NO. <u>—</u>   |
| K. INCLUDED FOR PROGRAM EVALUATION COSTING                 | NO. <u>100</u> |

#### NOTES OF EXPLANATION:

1.  $A - B = C$ ,  $D + E + F = C$ ,  $G + H + I = C$ ,  $J = C$ ,  $K = C$  The number (No.) of clients shown in each category from "D" to "K" inclusive are part of the client population noted in box "C", but the categories are not mutually exclusive.
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Adults Group 1 16-39 years, Group 2 40-60 years.



CLIENTS REQUIRING NEW PROGRAMS AND NEW STAFF

[illegible]

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76 Thornwood Close  
Calgary, Alberta  
T2K 5K3

Dear Mr. and Mrs.

Because of my involvement with the Calgary Community Planning Organization and particularly with the committee that is attempting to make recommendations on a new facility to replace the present Baker Sanatorium, as well as part of my graduate program in Social Work, I have chosen to study the services available for handicapped people. My special interest is in the area of the creation of the ideal residential facilities for those individuals who are profoundly or severely mentally handicapped and who have extended health care needs.

A profoundly or severely mentally retarded individual is considered that person who requires extensive support to maintain daily routines or life functions. Extended health care needs generally refer to those needs which require regular nursing care with some medical back-up.

Since the government is currently reviewing available facilities, it would be useful for them to be exposed to your needs. This should help in identifying any possible gaps in the creation of service facilities. Your experience and knowledge in understanding the needs of this level of handicap, could assist in designing better future services.

All your information will be treated with respect and confidence. No individuals or families will be identified. Please complete the enclosed questionnaire within one week and return it in the stamped, self-addressed envelope provided. If you require further information please feel free to contact me at 274-7911.

I am interested in you and your child's situation. My hope is that my research will be sensitive, expressing your needs and experiences and that this will be helpful in designing better future services.

Sincerely,

(Mrs.) Ilona Boyce

Enclosure

PLEASE DO NOT SIGN

## QUESTIONNAIRE

The following questionnaire is designed to gain an understanding of the needs of the severely and profoundly retarded who also have related health problems.

Please write the correct answer in the blank below the question or place a check mark in the box beside the appropriate answer.

1. Child's sex

---

2. Age in years

---

3. Birthplace

---

4. How handicapped do you judge your child to be:

mild	( )
moderate	( )
severe	( )
profound	( )

5. Does your child have related health problems?

Yes	( )
No	( )

↓

If yes: do you feel your child requires the services of a professional health person:

always	( )
very often	( )
about as often as not	( )
seldom	( )
never	( )

6. Do you feel the services provided by the province for the handicapped are:

adequate  
somewhat adequate  
inadequate  
grossly inadequate

( )  
( )  
( )  
( )

If inadequate, describe the inadequacy in terms of your child's needs.

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7. Is your child in a program currently?

Yes  
No

( )  
( )

If yes: Are you satisfied with the program's appropriateness for your child?

Yes  
No

( )  
( )

If no: Please comment on what you would like to see changed.

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8. If your child is living at home please answer the following question; if not, proceed to question 9.

(a) How difficult do you find it to care for your child at home?

not difficult  
somewhat difficult  
very difficult  
breaking point

( )  
( )  
( )  
( )

- (b) Do you anticipate a time when you will require the care provided by a special residence?

Yes  
No

( )

If yes: please indicate what you feel you would like to see made available to your child.

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Proceed to question 10.

9. If your child is living away from home please answer the following question.

My child is presently residing with:  
another family ( )  
residence for the handicapped ( )  
other (please specify) \_\_\_\_\_

If your child is in a residence are you satisfied with the care:

yes ( )  
no ( )

If no, please specify what changes you would like to see.

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10. In planning for a residential facility for these individuals what do you feel are important factors to consider in terms of:

(a) Physical comfort  
Comment: \_\_\_\_\_

\_\_\_\_\_  
\_\_\_\_\_

(b) Individualization  
Comment: \_\_\_\_\_

\_\_\_\_\_  
\_\_\_\_\_

(c) Location of facility  
Comment: \_\_\_\_\_

\_\_\_\_\_  
\_\_\_\_\_

(d) Ideal size of facility  
Comment: \_\_\_\_\_

\_\_\_\_\_  
\_\_\_\_\_

(e) What do you feel are important considerations in terms of staff?  
Comment: \_\_\_\_\_

\_\_\_\_\_  
\_\_\_\_\_

(f) Do you feel that the special care needs of the residents should generally be met by:

specialists

general services in the community

( )  
( )

Comment: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

(g) Should the program be integrated into the community?

Yes ( )  
No ( )

(h) Do you feel it is important that children and adults be separated by age?

Yes ( )  
No ( )

Comment: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

(i) Do you feel all the levels of handicapped should be serviced in the same geographic area?

Yes ( )  
No ( )

Comment: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

(j) Who do you feel should administer such a facility?

Community Boards ( )  
Parent's Association ( )  
Government ( )  
Other (please specify) \_\_\_\_\_

Comment if desired: \_\_\_\_\_

\_\_\_\_\_

11. Finally I'd like to know a little about you so that I am able to have a better understanding about the areas being studied. Please place a check mark in the space beside the appropriate answer or write in the correct answer.

(a) Marital status of the head of the household.

single ( )  
divorced ( )  
separated ( )  
married ( )  
widowed ( )

(b) Age of the head of the household in years

\_\_\_\_\_

(c) Age of spouse in years (if applicable)

\_\_\_\_\_

(d) Area of the city where family resides

Northwest	( )
Northeast	( )
Southwest	( )
Southeast	( )

(e) In which of these groups did your total family income, from all sources, fall last year, before taxes.

under \$10,000	( )
10,000 to 19,999	( )
20,000 to 29,999	( )
30,000 to 39,999	( )
40,000 or over	( )

12. Any additional comments you may wish to make.

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